

Assessing the promise of user involvement in health service development: ethnographic study

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ABSTRACT

Objectives To understand how the policy of user involvement is interpreted in health service organisations and to identify factors that influence how user involvement is put into practice.

Design Ethnographic study using participant observation, interviews, and collection of documentary evidence.

Setting A multiagency modernisation programme to improve stroke services in two London boroughs.

Participants Service users, National Health Service managers, and clinicians.

Results User involvement in the programme was initiated and led by professionals. Professionals determined the areas of service improvement service users could participate in. A wide range of activities were considered "user involvement," from patient satisfaction surveys to service users delivering peer support. Involvement tended to be most active in the least technical areas and areas with least input from clinicians. Factors that might explain this included organisational structure, the vagueness of the concept of user involvement, the value attributed to service users' experiential knowledge, and variations in professional and service user understandings of and commitment to involvement. The gains of involvement were harder to identify in terms of impact on services. More evident were the personal gains for those involved: satisfaction of feeling listened to by professionals, social opportunities of meeting others in a similar situation, and increased knowledge about stroke and services available.

Conclusions User involvement may not automatically lead to improved service quality. Healthcare professionals and service users understand and practise user involvement in different ways according to individual ideologies, circumstances, and needs. Given the resource implications of undertaking user involvement in service development there is a need for critical debate on the purpose of such involvement as well as better evidence of the benefits claimed for it.

INTRODUCTION

Reforms to the United Kingdom's National Health Service include encouraging patients to exercise greater control over their health care and to become more involved in the development of health services.¹⁻³ The Department of Health promotes the involvement of patients and the public in decisions about the planning, design, development, and delivery of local services, with the promise that this will lead to improved services and better outcomes for patients.⁴ Policy documents are, however, less clear about how involvement should be undertaken.

We carried out an ethnographic study⁵ of an initiative to involve people with stroke and their relatives (service users) in the modernisation of stroke services.

METHODS

In 2004 a three year programme of service improvement was initiated to modernise stroke services in two London boroughs. The programme, delivered by NHS employees and clinicians, aimed to reduce the number of first time strokes and to modernise stroke services.

Fieldwork began in December 2004, before service users were recruited, and continued for two years. It consisted of participant observation, collection of documentary evidence, and semistructured interviews (see bmj.com) to record how user involvement was implemented and maintained, and data on participants, activities, and outputs. Participant observation entailed working with programme staff, participating at recruitment events, and programme meetings. NF made ethnographic notes and kept a reflexive diary.⁶

We carried out semistructured interviews with service users and programme staff who had worked closely with service users (see bmj.com). Interviews were tape recorded and transcribed.

We carried out thematic analysis of the notes, diary, transcripts, and programme documents. Analysis was done concurrently with data collection and iteratively directed data collection.⁷ Every three months NF wrote a summary of the fieldwork and identified emerging themes, patterns, categories, and anomalies. The notes, diary, and programme documents were reread to code additional patterns and themes. These were discussed and iteratively reviewed with CM. We grouped these patterns and themes into larger overarching themes. The emerging themes were reported to programme staff and service users to identify additional data that might challenge preliminary analyses.⁸

RESULTS

From the outset user involvement was considered an important part of the programme. Programme documentation announced that service improvement would be achieved through "close collaborative working with people who have stroke in designing and delivering integrated services to support all stages of treatment, rehabilitation and learning to live with stroke." No specific detail was given of how this was to be achieved. The programme was organised into four work streams overseen by a management group (figure). The fourth work stream focused on user involvement, development of the workforce, and information. A manager was employed to lead on

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user involvement throughout the programme, supported by a working group. Initially this comprised 12 people from local voluntary sector and health service organisations, although membership decreased to five after two meetings.

Recruiting and directing service users

Invitations were distributed to stroke survivors using consecutive and convenience sampling through a community stroke register, voluntary groups, and clinicians. Sixty service users attended the two initial events. Overall, details of 176 service users (158 stroke survivors, 18 carers) were entered on a database over the two years.

Service users who attended recruitment meetings were invited to identify their priorities for stroke service improvement. Programme staff recorded these problems. Staff encouraged attenders to participate in one or more activities from a list: training healthcare professionals, developing information, providing peer support, ensuring stroke survivors were involved in the programme, and membership of the programme management group. Training was offered to service users who wished to participate in peer support, training healthcare professionals, and the project management group. Professionals who were already members of the management group were also offered training about working with service users (figure).

User involvement activities and outputs

Over two years the programme succeeded in engaging users to produce a range of outputs aimed at improving specific components of stroke care (see bmj.com). Intuitively some outputs would seem to have higher quality because of the involvement of users.

When asked about how their involvement had improved services, few service users could directly answer the question. They pointed to specific new services initiated within the programme such as peer support and events to raise awareness of stroke held at general practices, both needs identified during consultations with service users. However, they discussed the impact of involvement primarily in terms of personal gains. During fieldwork it was common to hear service users remark that this was the first time that they had met another stroke survivor. Throughout the programme service users were observed engaging with the programme for the social opportunities it provided. Service users also described their involvement as helping to increase their knowledge and understanding of stroke.

Factors limiting service user involvement

Users were involved in a variety of projects although this was mainly restricted to those in the infrastructure work stream, and service users were less likely to be involved in technical projects. Several factors might explain this.

Organisational structure and responsibility for user involvement

The appointment of a user involvement lead and establishing a specific group for user involvement meant that user involvement became a distinct project and was harder to embed throughout the programme. The lead described her situation as a catch 22 one—it was necessary to have a person dedicated to user involvement but this meant colleagues could leave “doing user involvement” up to her. She could encourage colleagues working in other work streams to involve service users in their work but did not have the authority to require it or control the form that it took. Not surprisingly user involvement was most developed in the infrastructure work stream. User involvement in the discipline specific work streams tended to take a more passive form, with use of, for example, patient satisfaction surveys and suggestion boxes.

Communicating involvement

Service users were more interested in participating in projects related to training healthcare professionals, developing information, and supporting stroke survivors than taking on management roles. Of five service users who underwent training to participate in the management group only two retained their membership. No service users were interested in joining the user involvement subgroup—a group to manage the involvement of service users in the programme—whereas the training, information, and peer support related projects had up to 15 members. When recruiting to these projects, staff could point to tangible outputs or products, such as developing good practice guidance to inform staff training, unlike other projects with less tangible outputs such as project management.

Types of knowledge

Projects that service users were involved in required them to draw on their experience of being a patient or carer. Programme staff promoted experiential knowledge as useful for educating health professionals and supporting other stroke survivors.

Clinical service development was seen to require a different kind of knowledge. Evidence suggests that professionals believed service users would not be capable of participating in some aspects of the programme because they lacked the necessary technical knowledge.

On several occasions during fieldwork incidents were observed suggesting that “involvement” requires both professionals and service users to reconceptualise the traditional category of patient to accommodate the notion that service users have a contribution to make, a transformation not always easily achieved:

“The user involvement lead and I arrived at the surgery where the event to raise awareness about stroke was to take place. The service users, who were part of the planning group and would help run the event, were already there in the surgery waiting room. The user involvement lead went up to the front desk and asked

the receptionists where we should go for the stroke raising awareness event. One of the receptionists got up from behind the front desk and began to lead us through a side door into the larger room where the event was going to be held. The receptionist tried to stop the service users from entering the room, telling them that the event wasn't due to begin for another

hour or so. The user involvement lead had to explain to the receptionist that these people were part of the organising team and that although they had all had strokes they were not patients from the GP surgery wanting to attend the event. The receptionist reluctantly let us all through." (*Field notes from an event to raise awareness of stroke, 7 December 2005*)

Project management group							
Role: oversee running of programme							
Users involved? Two service users join group as members							
Four work streams to oversee day to day running of projects to improve stroke services:							
Prevention Work stream lead: clinician. One service user on steering group		Acute services Work stream lead: clinician.		Community services Work stream lead: primary care trust service managers		Living with disability Work stream lead: co-led by voluntary sector and one service user	
Project	Users involved?	Project	Users involved?	Project	Users involved?	Project	Users involved?
Improving blood pressure monitoring in general practices	Through steering group discussions and discussions with service users on local groups to oversee implementation	Transient ischaemic attack clinic	Service users consulted on design of patient questionnaire. Shadowing patient walk through of service	Mapping community service usage	None	User involvement	None – service users invited to join, but no interest in this group
Scoping for project on telemedicine	None	Improving ward environment	Patient questionnaires, suggestion boxes	Intensive community rehabilitation	One patient wrote in with feedback having received service	Information	Information group of 15 service users established. Worked on: developing information pathway, patient held records, information leaflet for stroke unit, picture boards for stroke unit, and information for parenting after stroke
Raising awareness of hypertension	None	Thrombolysis and acute response	None	Developing staff competencies	Service users consulted at sign off event for developing staff competencies	Workforce training	Training group of 15 service users established. Created DVD of patients' experiences of stroke with guidance on how patients want to be treated by professionals. Service users involved in training healthcare professionals
				Goal setting in rehabilitation	One service user attended training events to launch scheme to professionals	Peer support	Six service users trained to give peer support
						Long term support project	Twelve service users involved in setting up network to provide people with stroke with long term support
						Raising awareness of stroke	Seven service users working with professionals to run events for local population in general practices to raise awareness of stroke

Structure of programme and projects done to improve stroke services. Shaded areas represent areas of programme where service users were involved

Patient and professional understandings of involvement

Professionals had a variety of views of what involvement entailed, linked to their own background and career history. Professionals responsible for involvement and those happy to undertake involvement had experience of involving service users in their work, tended to have backgrounds in voluntary and social care fields, and tended not to be involved in the more clinical and technical aspects of the programme. These professionals displayed a moral and political commitment to the ethos of involvement and belief in the engagement of citizens in public decision making. Other professionals saw involvement as a NHS requirement.

Service users gave a range of reasons for participating in the programme, which suggests that involvement was not understood solely as an opportunity to be involved in service development. Motivation to participate included the right for patients to have a say about the services they use, the chance to meet others in a similar situation, finding out about developments in stroke medicine, accessing health or social care services, and attending as part of the process of recovery from stroke:

“I spoke to Mr Roberts about the Join In Event and whether he was able to come or not. Mr Roberts said the he wasn’t sure he’d ‘get much value out of the meeting.’ Mr Roberts explained that he had had a mild stroke and apart from memory loss and slight vision problems was ‘reasonably fit.’ He said that he ‘couldn’t see how [he] could contribute much.’ Mr Roberts said that he thought that the meeting is basically needed for other people more badly affected by stroke.” (*Field notes from telephone conversation, 5 October 2005*)

DISCUSSION

Involving service users in service development is an NHS policy requirement promoted to encourage patients to exert greater control over their health care and improve health services. Our ethnographic study shows that although the programme embraced the policy of user involvement and aimed to involve users in all its activities, programme staff largely determined how user involvement was put into practice. Little evidence was found of user involvement directly contributing to improved quality of services except in a few limited areas. The contribution of service users centred on the application of their experiential knowledge to develop services and materials to deliver peer support, information, and staff training. Their lack of technical knowledge was seen to preclude their participation in some activities. Thus, as other studies have found, professionals control the interpretation of involvement and the ways that service users are involved.⁹⁻¹²

Concepts of involvement

We found that different concepts of user involvement coexisted within a single organisation. As user involvement was loosely defined in programme

documentation there was little dissent about whether activities constituted “real” involvement. We observed differences within professional and service user groupings based on individual ideologies, circumstances, and needs. Within professional groupings we identified two categories—those who viewed user involvement as an exercise in democracy and promoted patients’ expertise as valid as that of professionals and those who unquestionably enacted out the policy of involvement as a directive to be implemented as part of a patient centred NHS.

Despite some promoting the philosophy of patient expertise, the domains in which patients could exert their expertise were limited. The involvement of stroke survivors in the clinical work streams was limited to more passive forms of involvement, such as patient satisfaction surveys or one-off consultations. This compared with involvement in areas such as training healthcare staff, developing information, and peer support where user involvement was more extensive and service users were more active in the development and delivery of these services. Thus user involvement in this setting did not transform patient and professional relationships in the way that policy documents promoting involvement imply.

Among services users we observed several motives for participating in the programme: desire to improve services, social opportunities, increasing knowledge of stroke, and accessing services. Although it is probably necessary for those involved to have a range of benefits in return for their participation, the implication of this calls into question the ability of user involvement to improve services if this is not the primary motivation of those involved.

Despite the significant impact of stroke on patients and family members who care for them^{13 14} and the long history of poor quality stroke services in the UK,^{15 16} user involvement in the specialty of stroke is only now beginning to emerge. Patients with stroke have not organised themselves into activist movements, as has occurred in areas such as HIV/AIDS.¹² Among the stroke population is a high proportion of older adults, people with disabilities, and those who are socially isolated.¹³ This raises questions about whether characteristics of certain patient groups affect the implementation of user involvement.

Representativeness of service users

Only a small percentage of the prevalent stroke population was involved, and those most active were a small, dedicated group of service users, with most participating in more than one project within the programme. The resources (time and money) required to recruit and sustain this small group were considerable, which raises two questions: how do we justify the cost of user involvement when the outcomes are unclear, and how representative of the stroke population was this small group of service users?

WHAT IS ALREADY KNOWN ON THIS TOPIC

Involving patients and the public in health service development is said to lead to better services and improved outcomes

Evidence showing the effects of this on the quality and effectiveness of services is limited

WHAT THIS STUDY ADDS

Professionals determine how service users will be involved in service development and this may limit change that can be achieved

Small numbers of service users were "involved," with personal gains for them

Service users' experiential knowledge is valued because it seems to provide information that will improve delivery of care

Promoters of involvement have insisted that we focus on inclusion and diversity of service users rather than representativeness.¹⁷ Our research suggests that more work is needed to ascertain whether the views of those involved are the same as those not involved and whether user involvement is leading to inequalities—providing benefits only to those involved. The small numbers of service users involved and the range of interpretations of what involvement is also question the assumption of user involvement policy that patients and the public universally want to participate in making decisions about health services.¹⁸

Strengths and limitations of the study

Our study has several limitations. Firstly, our ethnography of a unique programme to modernise stroke services is not immediately generalisable to other examples of service modernisation in which service users are involved. The questions we raise from our findings are, however, applicable more broadly to the policy of user involvement. Secondly, our evaluation was carried out over two years of a three year project. Thirdly, the ethnographic approach we have taken is an interpretive one and does not provide the only or most legitimate account.⁵

Other studies looking at user involvement in practice have tended to use qualitative methods such as interviews.^{9,10} The strength of this study is the ethnographic approach incorporating participant observation over a sustained period allowing observation of insider insights and what participants actually do as opposed to what they say they do.¹⁹

Implications for policy and practice

In terms of practice our ethnography suggests that the presumed benefits of the policy may not be easily achieved. Our study has shown that a small proportion of the stroke population actively participated, raising questions about who gets involved and

whether this might lead to inequalities if only a small group experience the benefits of involvement. It is perhaps also an assumption of the policy that everyone wants to be involved. Characteristics of the patient group involved may also determine the form that user involvement takes and the time it takes to embed within an organisation. Unlike the classic examples of activist led involvement (for example, HIV/AIDS), user involvement in this study was professionally led. As a result of the multiple meanings, philosophies, and outcomes of involvement, user involvement will not necessarily be able to generate radical change to health services as the policy might suggest.

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