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Engaging service users in the development of stroke services: an action research study

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Aims and objectives. To develop local stroke services by involving, in a meaningful way, those affected by stroke in identifying and prioritising service development issues.

Background. Consideration should be given to including the views of service users in the evaluation and re-design of services. In stroke, the involvement of patients and carers in the development of services has generally been at a consultative level. There is a need to explore strategies to engage patients and carers more fully with the service development agenda.

Design. Action research.

Methods. Within the Reflection Phase of this action research study patients' and carers' experiences of stroke services were explored by semi-structured interviews and focus groups. In the Planning and Action Phases, externally facilitated workgroups comprising patients, carers and professionals used a synthesis of the data to identify a range of service development priorities, which informed the development of action plans.

Results. Information provision, preparation for transfer of care and the integration of social and leisure activities appear to be priorities for the development of stroke services from the perspective of patients and carers. These findings informed the work of four collaborative workgroups to lead developments in the stroke pathway as follows: stroke prevention and immediate care, early and continuing rehabilitation, transfer of care and long-term support and information provision.

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Conclusion. Stroke patients and carers played a key and meaningful part in the identification and prioritisation of service development issues. External facilitation ensured progress with service development and maintaining patient and carer participation. Several pragmatic recommendations for enhancing the local delivery of stroke services were made.

Relevance to Clinical Practice. With external facilitation it is possible for stroke service users to take a meaningful role in service developments that moves beyond consultation.

Key words: carer, experience, involvement, participation, partnership, patient, stroke, views

Introduction

The National Service Framework (NSF) for Older People provides a clear impetus for the involvement of patients in the development of stroke services in the United Kingdom (UK). Specifically, they should play 'their full part in local planning and implementation, advising on priorities, providing feedback on progress and acting as a reality check' (Department of Health 2001, p. 114). This establishes a new role for stroke patients and carers at the centre of the design, evaluation and improvement of stroke services.

While there is evidence to suggest that some patients would like to be involved in decision-making processes, little is known about the circumstances in which shared decision-making should be encouraged (Coulter 1997, Entwistle *et al.* 1998). Furthermore, there is a paucity of evidence to support shared decision-making in practice (McCrae *et al.*, Edinburgh University, Edinburgh, unpublished paper).

Involvement requires that a non-paternalistic approach to engagement with patients is adopted, which acknowledges the priorities and aspirations of individual patients (Cahill 1998). This shift towards patient-centred as opposed to professionally-driven care requires that information, decision-making, evaluation and responsibilities are shared between patient and professional (Coulter 1999). This may only be facilitated by an open discussion between professional and patient, which seeks to narrow the information and knowledge gap between them (Cahill 1996) and takes account of the potential differences in the type of knowledge and language used by both (Ashworth *et al.* 1992, Guadagnoli & Ward 1998).

Several models of patient involvement have been used in health services (Arnstein 1969, Small & Rhodes 2000, McCrae 2002). The 'ladder of participation' (Arnstein 1969) identified that simple consultation should be seen as tokenism and that partnership was the most effective route to achieve patient empowerment (Arnstein 1969). There are, however, many challenges to achieving partnership in service development including differences between lay and professional knowledge and language and imbalances in power emerging from healthcare funding strategies where service users hold little or no financial power to influence decisions. While there is no clear consensus about the desired level of involvement in UK health services, the NHS Modernisation Agency (2002) proposes an extensive involvement strategy, which includes multiple techniques to uncover service user perspectives on the current configurations of services. The challenge remains, however, to ensure that these perspectives are fully incorporated into the development, implementation and evaluation of service re-design.

In stroke services, there are two main areas where service users may be involved (Barnes & Wistow 1992). Firstly, involvement can be specific to choices about the management of an individual's care and treatment options. Secondly, involvement can be a feature of strategic management, where the views of service users directly inform the development of service policy and delivery. The latter type of involvement is more difficult to achieve, with few established models to facilitate involvement at a local level beyond consultation.

Literature review

A review of the literature was undertaken to identify the range of strategies for service user involvement in stroke services. A search of electronic databases (Medline, CINAHL and AMED) was carried out to identify literature published from 1995 to 2005, using a combination of the following keywords: stroke, partnership, participation, experience, preference, view, involvement and satisfaction combined with patient and consumer. Criteria to select papers for inclusion included a focus on service user views of stroke services and those that were published in English in peer-reviewed journals.

A total of 180 potential papers were identified and papers relating solely to the experience of stroke as a disease, or views on single or novel interventions were excluded. Eighteen studies that sought to involve patients and carers in the development of stroke services were obtained for critical appraisal. A manual search of reference lists did not identify any additional papers.

The studies were categorised according to when patients were recruited: acute stages of stroke (von Renteln-Kruse *et al.* 2002), early and continuing rehabilitation (Clark & Smith 1998, Bendz 2000, Proot *et al.* 2000, von Renteln-Kruse *et al.* 2002, Wiles *et al.* 2002, Hale *et al.* 2003, Bolsche *et al.* 2004, Wohlin Wottrich *et al.* 2004), transfer of care and long-term support (Tyson & Turner 2000, Martin *et al.* 2002, Simon *et al.* 2003, Bolsche *et al.* 2004) or all of the recovery pathway (Thomas & Parry 1996, Tyson & Turner 1999, O'Mahoney *et al.* 1997, Reker *et al.* 2002, Sulch *et al.* 2002, Walldal *et al.* 2002).

The studies all described involvement at a consultative level, using mostly interviews (Pound *et al.* 1995, Thomas & Parry 1996, Clark & Smith 1998, Bendz 2000, Proot *et al.* 2000, Martin *et al.* 2002, von Renteln-Kruse *et al.* 2002, Wiles *et al.* 2002, Hale *et al.* 2003, Simon *et al.* 2003, Wohlin Wottrich *et al.* 2004) and questionnaires (O'Mahoney *et al.* 1997, Tyson & Turner 1999, 2000, Reker *et al.* 2002, Sulch *et al.* 2002, Walldal *et al.* 2002, Simon *et al.* 2003, Bolsche *et al.* 2004) to capture views and experiences. Two of the studies prospectively explored service users' views regularly throughout the stroke service (Clark & Smith 1998, Wiles *et al.* 2002). The remaining studies relied on obtaining retrospective information.

The most consistent finding from these studies was inadequate information provision (Pound *et al.* 1995, O'Mahoney *et al.* 1997, Tyson & Turner 1999, Simon *et al.* 2003). Despite this, those studies that used a patient satisfaction questionnaire found that patients were generally satisfied with stroke services (Thomas & Parry 1996, Clark & Smith 1998, Reker *et al.* 2002). While many of these studies recognised the importance of using information gleaned from experience to underpin stroke service development, no studies included clear plans for doing this, or in enabling patients and carers to play active roles in designing and evaluating service developments.

The study

Aim

This study aimed to develop local stroke services by involving, in a meaningful way, those affected by stroke.

Objectives

Specifically, the objectives were to:

- identify and prioritise issues raised by stroke service users to guide the development of services;
- facilitate service user involvement in the process of stroke service development.

Study design

An action research framework was adopted to ensure that the experiences of service users were used to underpin the development of services. As a methodological paradigm, action research is well suited to this research aim because it encourages participation and focuses on problem solving (Waterman *et al.* 2001).

Action research is presented as a cycle of problem identification, which involves reflection, planning, action and evaluation, although in practice it may not be possible to go through each stage of the cycle (Waterman *et al.* 2001). Within this study, the Reflection Phase involved identifying service user experiences of stroke services through qualitative enquiry. These experiences were then used in the Planning Phase to guide the development of plans for stroke service redesign. The Planning and Acting Phases involved collaboration between service users, professionals and research staff.

Role of researcher

Within action research, the researcher and study participants are actively involved in all stages of the process. The researcher often has a close relationship to the participants, which may help to promote change in practice (Waterman *et al.* 2001). Within this study, the action researcher (SJ) had no formal relationship within the stroke service participating in the project. While the project had been commissioned by the service, presentations about the purpose of the project and informal discussions with members of the clinical team were used to facilitate entry to the study site and establish working relationships within the context of the study.

Setting and samples

The study was undertaken across one Primary Care Trust and three Acute Hospital NHS Trusts in one metropolitan area in the North West of England. To ensure that a broad range of views from patients and carers were captured in the reflection phase, purposive sampling was used to identify participants of both sexes, from different age groups and who had experienced stroke services in one of three participating hospitals. In addition, attempts were made to ensure representation of those with cognitive and communication difficulties, as these consequences of stroke would have a major impact upon individual experiences. Patients with a clinical diagnosis made by a member of the clinical team were highlighted on stroke registers. Twenty eight patients, 18 of whom had carers, were consented to take part in interviews. Two carers consented independently to be interviewed, because the patient had severe cognitive and communication problems which excluded them from consenting. The sample characteristics are representative of all stroke patients registered during the recruitment period.

To obtain the long-term experiences of people living with stroke, a further sample of stroke service users were identified through General Practitioner (GP) stroke registers in the community. The only inclusion criterion for this sample was that their stroke must have been in the last two years. Of 28 possible participants, five patients and two related carers consented to take part in the study and their characteristics are also reported in Table 1.

Data collection

A combination of semi-structured interviews and focus groups with both patients and carers were conducted in the Reflective Phase of the study. Interviews sought service users' understanding of what happened throughout the contact with the stroke service and the degree to which this met their needs. Focus groups explored the concept of an 'ideal' stroke service, including what practical issues needed to be addressed at each phase of the pathway. To ensure relevance, both interview and focus group questions asked were underpinned by a policy framework (Fig. 1), reflecting the NSF (Department of Health 2001) four main components for the development of integrated stroke services: prevention, immediate care, early and continuing rehabilitation, transfer of care and long-term support.

Framework level	**Dimensions**			
1. Four main areas of the stroke pathway	Prevention	Immediate care	Early and continuing rehabilitation	Transfer of care and long-term support
2. Attitude dimensions	Positive		Negative	
3. Descriptors	e.g. 'Impact on Family'			

Figure 1 Policy framework for the collection and analysis of data.

Table 1 Characteristics of samples within reflective phase of the study

Participants	
Patients recruited from hospitals (*n* = 30)	
Median age (range)	72 (35–90)
Gender (% female)	53
Median days in hospital (range)	39 (1–214)
Number with communication or cognition problems (%)	9 (30)
Patients recruited from community (*n* = 5)	
Median age (range)	70 (25–92)
Number (%) females	52
Median days in hospital (range)	31 (2–123)
Number with communication or cognition problems (%)	2 (40)

For those patients and/or carers recruited through the hospitals, interviews took place as soon as practicable after admission as well as during their stay, before discharge and at one and six weeks postdischarge. Participants were asked at each stage to discuss their journey from the first signs of stroke adding their most recent experiences. This allowed for comparison with earlier interviews and cueing participant's memories for experiences that may have been omitted previously. When the interviews were completed, participants were invited to take part in one of three focus group discussions, one at each of the hospital sites. All interviews and focus groups were fully transcribed. Participants recruited in the community were interviewed once at their place of residence.

Data analysis

According to Morse and Field (1995), there are four cognitive processes involved in qualitative data analysis: comprehending, synthesising (de-contextualising), theorising and re-contextualising. To achieve these stages, the transcripts were read in depth and codes were assigned using a program for textual analysis. The codes were categorised according to the policy framework (Figure 1) and related to the relevant NSF component, the attitude intended by the participant (positive or negative) and a descriptor that could categorise the text. All descriptor codes were established after analysing an initial sample of eight transcripts by two of the project staff (SJ and MA) and these were verified by an external assessor.

Credibility

Credibility in the interpretation of qualitative data was addressed by the combination of real-time interviews and retrospective interviews and focus groups. In addition, summaries of interviews were sent to participants to check for accurate representation of their views. There is evidence in the literature to support this practice with many authors advocating that the researcher return to the participants to verify the research findings (Guba & Lincoln 1981, Turner 1981, Lincoln & Guba 1985, Brink 1991, Ashworth 1993, Leininger 1994).

Memos were created using the analysis software that detailed how decisions were made in relation to codes. A second researcher audited the completion of all study processes and coded a sample of transcripts to verify the coding process. This enabled each issue raised by participants to be traced through extracts to its original context (Guba & Lincoln 1981). Any lack of agreement between the two researchers was also noted and resolved through discussion.

Ethical considerations

Ethical approval for the study was provided by the Local Research Ethics Committees. All participants were given the opportunity to ask questions prior to written informed consent being obtained. Patients and carers were assured that confidentiality and anonymity would be respected. Patients with mild to moderate cognitive and communication problems were invited to take part in the study if staff and the patients' carer felt that this would be appropriate. As patients with severe cognitive and communication problems were unable to provide informed consent, carers of these patients were asked to take part in the study.

Findings

The experiences of patients and carers throughout their stroke journeys generated a range of issues for service development and are organised under the policy framework described earlier.

Prevention

Almost all patients and carers identified a lack of information around how to prevent another stroke, including uncertainty about stroke prevention medication that had been prescribed. A lack of information about how the modification of lifestyle factors including smoking, diet, cholesterol, alcohol, could prevent a further stroke was evident:

> You would have thought there would have been perhaps just a little package to say high cholesterol avoid these foods. High blood pressure don't do this. But I'm assuming the cigarettes, giving those up would maybe stop the high blood pressure. Or maybe you were over weight, I don't know. (Male, carer)

Immediate care

The main area of concern relating to immediate care was a lack of knowledge in being able to recognise the symptoms of stroke and who should be contacted for help. The signs and symptoms of stroke are not commonly known among the general public and, in particular, in groups that are at the highest risk of having a stroke (Brice *et al.* 2002). Half of all patients in the study had contacted a GP before going into hospital. Even after contacting a GP, some patients and carers were still unsure as to what course of action they should take:

> My husband was worried and I think he had a chat with the doctor. Then my daughter came because he rang her and said he was worried and didn't know what to do. So she came as well. (Female, patient)

One of the key objectives within the NSF for immediate care is the provision of an accurate diagnosis. Service users highlighted the need for communication about their diagnosis to be delivered in a sensitive manner. They often expressed difficulty in identifying different health professionals, even when a member of staff informed them of their diagnosis:

> Oh straight away one woman came and said you've had a stroke… I was shocked then. (Female, patient)

Early and continuing rehabilitation

Service users described in some depth their experience of rehabilitation while in hospital. Practical advice given by therapists was appreciated, including for example, guidance given by physiotherapists about how to get up if they had a fall:

> How to get up if I fall. Very useful, hold onto this chair and pull myself if I can. (Male, patient)

Activities that they could carry on outside formal therapy sessions or 'homework' were felt to promote positive feelings about recovery. Many outlined the benefits of activities that had a wider social meaning:

> Sometimes we read the headlines in the paper and discussed the outcome and various things… I enjoyed the quizzes because I knew a few of the answers. Doing little things like that helped rather than just sitting on the ward waiting. (Male, patient)

Again a perceived lack of information about rehabilitation was evident and both patients and carers wanted further information about individual progress and recovery. Some felt that they wanted to do more for themselves but were unsure as to whether they should try some activities without the assistance of a member of staff:

> There didn't seem to be a consistent policy as to whether in fact I should be escorted or whether somebody should hold my arm or

> walk behind me. You begin to wonder, what am I supposed to be doing? (Male, patient)

Recovery was generally viewed as a process of attaining goals, set by both the patients themselves and/or staff. Advice about what goals they should set themselves, as well as the current and future goals of nurses and therapists was required. There was often uncertainty as to how rehabilitation activities were contributing to the achievement of goals, but it was assumed that they must somehow be of benefit:

> I had to play pontoon with him (the Occupational Therapist). Stood up, I had to throw hoops. You might think it's silly but they all must count mustn't they? (Male, patient)

Transfer of care and long-term support

Carers in particular would have liked to be more involved in planning for transfer to the community. Many were anxious about whether they would be able to cope, what help they would receive and had concerns about whether the patient felt ready to leave hospital. Although some patients and carers reported involvement in a well co-ordinated discharge process, some were not involved at all and found this very difficult:

> I went in to visit her and they said 'are you taking her home.' Luckily I was with a neighbour. She gave me a lift home to get her clothes and brought me back. Then we brought her home. (Male, carer)

When patients had been transferred back into the community, they often felt a sense of abandonment. Many assumed that their GP would visit them at home to review their progress. They described feeling disappointed and unsure about what follow-up services they would receive. They also tended to be unsure about postdischarge therapy appointments. Although service users were expecting physiotherapy for example, they did not know how long they would have to wait for therapy, who they should contact for advice and if therapy sessions would take place at hospital, at a facility in the community or in their own home:

> They tell you that they're sending someone to see you and then you never see them. I mean it's not a place you can't find. But they don't send them or should I say they don't care. (Female, patient)

Planning and acting phases

Our intention was to establish and facilitate workgroups involving patients, carers and staff to prioritise issues and develop collaborative action plans for service development. One hundred and thirty service users, healthcare professionals, members of voluntary and charity organisations attended an initial meeting facilitated by the research team to consider the findings from the Reflection Phase (Table 2).

Attendees were asked to volunteer themselves to form four workgroups. Each workgroup was responsible for the issues related to one component of the NSF. Sixty three people nominated themselves to take part in a workgroup. The function of the workgroups was to prioritise the issues they had elected to work on and then propose a development recommendation. At the first workgroup meeting, a detailed overview of relevant quotations from the reflection phase of the study was provided and discussed and a service development need prioritised. The second meeting provided an opportunity to consider strategies for action planning. Subsequent meetings provided opportunities for individual workgroup members to report on progress with action plans. Table 3 provides an overview of the membership of each workgroup, indicating that service users were the largest constituency in each.

At each stage of the study, specifically designed information sheets and newsletters were circulated to all service users.

Table 2 Service development issues generated from Reflection Phase data

Prevention	Immediate care	Early and continuing rehabilitation	Transfer of care and long-term support
Service users would like information about medication	Some service users are unable to recognise stroke symptoms	Service users would like information about: current ability, intended goals, activities allowed, individual progress and recovery	Service users would like to be involved in a planned discharge
Service users would like information about risk factors	Patients with suspected stroke are not clear who to contact for help	Patients identified the benefits of activities that had a wider social meaning	Patients would like information about what to expect following discharge
	Patients would like communication about their diagnosis to be delivered in a sensitive manner	Patients appreciated practical advise that was given by therapists	Patients would like information about waiting times for therapy
			Patients would like information about who to contact for advice

Table 3 Constituency of workgroups in the planning and acting phases

Constituent members	Workgroups			
	Prevention and immediate care	Early and continuing rehabilitation	Transfer of care and long term support	Information provision
Service users	4	3	5	4
Consultant physician	1	1	0	0
Nurses	3	5	4	4
Physiotherapist	1	3	1	1
Occupational therapist	0	2	2	1
Speech therapist	0	1	2	1
Continence service	0	0	1	0
Social services	0	0	1	1
Voluntary sector	1	1	1	2
Research team	1	1	1	1

The facilitator contacted individual service users following the focus groups, initial meeting and after each workgroup for a debriefing discussion. During these discussions, any service user feedback was noted by the facilitator and considered at the next focus group or meeting. All meetings and workgroups were facilitated to ensure that service users were able to express their experiences and opinions, particularly in the process of stroke service development. Our intention was that each workgroup would nominate a facilitator who took over all responsibility of the workgroup from the researcher. However, this strategy proved to be difficult as facilitators did not feel that they could organise and support the workgroups over three hospitals taking part in the project. Clinical governance managers at each Trust were then contacted to assess the role that they could play in supporting the workgroups. This method of facilitation was found not to be suitable either, due to increasing commitments elsewhere. Therefore, the research team are continuing to organise, support and facilitate the workgroups. The workgroups were asked to choose one key priority from the reflection phase findings and to develop an action plan including responsibilities of workgroup members and timeframes.

Stroke Prevention and Immediate care priorities were merged into one workgroup. Their action plan focused on increasing public awareness of stroke symptoms and risk factors. A key priority identified within the workgroup was to ensure rapid access to the stroke service by encouraging people to use emergency rather than Primary Care services. The group developed information to inform the general public about stroke symptoms and action that should be taken.

The aim adopted by the early and continuing rehabilitation workgroup was to develop a programme of rehabilitation and social activities, informed by the suggestions of service users. The programme included a range of activities that provided opportunities for socialisation were relevant to the real world of service users and that incorporated elements of therapy. The workgroup discussed the contents of a new programme of rehabilitation and social activities. These activities have now been made available to patients and include, for example, group discussions, gardening and cooking activities.

The action plan developed by the transfer of care and long-term Support workgroup aimed to involve all patients and carers in their transfer into the community by developing strategies to promote carer involvement, providing home visits and overnight stays and developing individual discharge plans. Due to the complexity of issues within transfer of care and long-term support, this work has not yet been taken forward.

As information giving was a cross-cutting issue, representatives of each workgroup formed an information sub-group. This sub-group focused their activities on the construction of new information packs that incorporated the issues raised by patients, carers and staff. These include general information about stroke and a personalised section for recording the results of assessments, diagnostic tests, medication and individual rehabilitation goals. This has now been incorporated into new information packs at each of the three participating hospitals.

Evaluation of the service developments is ongoing and will be reported in due course. However, this study has demonstrated that it is possible to extend the process of participation of stroke patients and carers in service development beyond consultation. Stroke can cause a range of physical, psychological and social sequelae (Burton 2000), such as problems with mobility, depression and communication difficulties. The experience of applied stroke research held by the facilitators enabled the development of appropriate communication and practical strategies to support participation. External facilitation of planning activity does appear to be important both in ensuring progress with action plan development implementation, and also in maintaining patient and carer participation.

Discussion

Health policy advocates for greater participation of patients and carers in the development of services and frameworks in the literature provide an optimistic and challenging target of partnership (Arnstein 1969). In stroke service development, participation has rarely moved beyond consultation, with few examples of good practice available to guide more meaningful involvement. This study successfully involved patients and carers in identifying and prioritising key aspects for local stroke service development, but perhaps more importantly, engaged them in developing and implementing action plans around priority issues. An awareness of the disease related challenges that may affect the ability to participate, regular communication and external facilitation appeared to support this enhanced participation.

As with many previous studies (Wiles *et al.* 2002, Tyson & Turner 1999, 2000, Martin *et al.* 2002, von Renteln-Kruse *et al.* 2002, Walldal *et al.* 2002), information provision was identified as the key priority for most service users and carers across the stroke pathway. Inadequate provision and receipt of stroke information has important consequences for both adherence with secondary prevention and long-term psycho-social outcome for service users (O'Mahoney *et al.* 1997). In this study, both patients and carers wanted more detailed and individualised, information around medical diagnosis, investigations and tests, medication, rehabilitation interventions and information about stroke in general.

A lack of knowledge about stroke signs and symptoms was also evident in the data. Many factors contribute to delays in seeking treatment for stroke, but the principal factor is lack of public knowledge regarding stroke signs and symptoms. Stroke outcomes can be improved by timely care, including access to organised stroke care (Stroke Unit Trialists' Collaboration 2004) and thrombolysis. It is therefore vitally important that the public are able to recognise the symptoms of suspected stroke and at an early stage.

It seems self-evident that the promotion of social activities should be integral to rehabilitation. Furthermore, that people affected by stroke should be involved when considering what social activities should be provided. Traditionally, however, rehabilitation has focussed on promoting functional independence. If rehabilitation does not give people the opportunity to participate in social and other activities, both physical and psychological recovery may be impeded. An evaluation of an individualised, leisure-based intervention delivered at home was not shown to have benefits over and above existing functional approaches to rehabilitation (Parker *et al.* 2001), demonstrating the challenges of developing suitable strategies to improve services in this area.

The expectation of both patients and carers is that they should be involved in discharge planning at an appropriate stage. Information should also be provided about when discharge will take place. Our study demonstrated that preparation for transfer of care was a valued component of the stroke service and a key area for individual involvement in decision-making. This is especially important at transfer of care can be a difficult time for both the patient and their family (Burton 2000).

Study challenges

The involvement of service users in planning the delivery of health services is a key feature of current political initiatives to improve the quality of healthcare. No consensus on which methods of involvement are most effective in various different settings has, however, been reached. This project sought to involve service users in setting a local agenda for change through the identification of good practice and issues for development. Patients, carers and staff worked in partnership in making and in prioritising, several recommendations for service development that met the expressed needs of service users and that are congruent with the capacity for development in the local delivery of stroke services.

Engagement with clinical staff is critically important if the development of stroke services is to be successful. Techniques and strategies to shift ownership away from the researcher to staff can facilitate motivation and commitment to change and ensure that plans for development are both realistic and achievable. Our action researchers were outside the service, in that they had no formal role with any of the hospitals taking part in the project. The role of researchers was to facilitate each stage of the project, through exploring service users' views and experiences to supporting work group meetings. While it was hoped that an external research team would have an unbiased perspective of local stroke services, the importance of negotiating access and commitment to the project had to be considered.

Service user involvement shifted from consultation in the Refection Phase to partnership in the Planning and Acting Phases. While participation involves becoming involved or being allowed to participate in a decision-making process (Brownlea 1987) this may not necessarily involve the empowerment of service users (Brearly 1990). Service users had no additional power to influence stroke service developments and, as such, any higher level of participation could not be reached.

Action research has provided a framework that has facilitated the improvement of stroke services and that has recognised the importance of service user involvement. Although the workgroups were keen to take their service developments further, this may have been more successful if health professionals, in more influential positions had been involved from the outset.

Strengths and limitations of the study

The design of this study, where data were collected prospectively in 'real time' revealed experiences of stroke services that may have otherwise remained unexplored. To ensure that in-depth, context-specific experiences were identified, a limited purposive sample of stroke service users and their carers were recruited to the Reflection Phase of the study. The purpose of this type of study is, however, to provide exemplary rather than generalisable information and differs in design, method and size from more traditional approaches to research in healthcare.

Evidently, although several organisations contributed to the study, it was undertaken in one geographical location. As such, the specific findings may reflect a local context. The literature demonstrates, however, that our findings have currency for stroke services in general. Equally the methods used may be applicable to other stroke services which are seeking to involve service users in decisions about the ways in which care is provided.

Conclusion

The provision of information regarding stroke and individual management, preparation for transfer of care and the integration of social and leisure activities within formal rehabilitation appear to be priorities for the development of stroke services from the perspectives of stroke patients and carers. Useful insights can be gained, which are important to inform both the content of stroke services and how they are delivered.

It is possible to involve service users in service development activity; however, this needs to be carefully managed and probably externally facilitated. An action research framework provides a useful framework for involving service users and staff and ensuring that activity is meaningful and tangible.

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Contributions

Study design: CLW; data collection and analysis: SPJ, MFA, CRB; manuscript preparation: SPJ, MFA, CRB, CLW.

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