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The participation of stroke survivors in service development and research an ethnographic study

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Title: The participation of stroke survivors in service development and research
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The participation of stroke survivors in service development and research: an ethnographic study

THESIS

presented for the

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Nina Fudge

Division of Health and Social care Research

Guy's, King's & St Thomas' School of Medicine

King's College London

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Abstract

Policy to involve patients and the public in health service development and medical research has been widely promoted in the United Kingdom on the grounds that this will improve the quality of services and research.

This thesis investigates how stroke survivors were involved in two enterprises: the Transforming Stroke Services Project (TSSP) hosted in the NHS; and an established Stroke Research Programme (SRP) located in a medical school. Data were collected in an ethnographic study conducted over a three-year period in south London.

Drawing on Lukes' three-dimensional view of power and embodied health movement theory, the thesis considers the implicit claims of user involvement policy that involving the public in the work of professionals will lead to patient empowerment, creation of new forms of knowledge, and a transformation of unequal relations between patients and professionals.

In the TSSP, stroke survivors were positioned as 'partners' in the project to modernise stroke services, yet the parameters of the partnership were determined from the outset by professionals. Transformation of patient and professional roles was not a goal that stroke survivors engaged in the TSSP particularly shared, deferring to professionals as 'the experts'. In the SRP, user involvement activities were similarly determined by professionals, and were adopted to demonstrate policy compliance;

user involvement was given salience by being transformed into an object of investigation. Patients’ experiential knowledge was ascribed value of a different order to expert knowledge, which was incompatible with any transformation of traditional patient and professional roles.

User involvement policy is shown to borrow from embodied health movements in terms of discourse and concern with diverse forms of knowledge and action. Yet whilst user involvement policy opens up space for citizen engagement, seeking the resources of service users, it inhibits their capacity for protest; the policy prevents an Embodied Health Movement from forming, but creates a new bureaucratised form of biosociality.

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List of terms and abbreviations

ART	Anti-retroviral therapy
CBPR	Community-Based Participatory Research
CHD	Coronary Heart Disease
DoH	Department of Health
ECT	Electroconvulsive therapy
EHM	Embodied Health Movement
GP	General Practitioner
HCP	Health Care Professional
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
HSM	Health Social Movement
Involve	Body funded by Department of Health to promote public involvement in NHS, public health and social care research
IRB	Institutional Review Board
KCL	King's College London
MSM	Men who have sex with men
NHS	National Health Service
NIHR	National Institute for Health Research
PCC	Patient centred care
PCT	Primary Care Trust
PI	Principal Investigator
PPI	Patient and Public Involvement
RCT	Randomised controlled trial
SBTS	Singapore Blood Transfusion Service
SRE	Sex and relationships education
SLSR	South London Stroke Register (additionally referred to in this thesis as 'the Register')
SRP	Stroke Research Programme
SRPFG	Stroke Research Patients and Family Group (a research 'user group')
TSSP	Transforming Stroke Services Project
UIWG	User involvement working group
UK	United Kingdom

USA	United States of America

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Chapter 1: Introduction

Towards the end of 2004, I started employment as a research associate in the Stroke Research Programme (SRP) at King's College London (KCL). The project I was to work on was to establish and evaluate patient and family participation in stroke-related health research and service development. Through my Masters in Environmental Epidemiology and Health Policy and a previous research position investigating the effects of air pollution on health, I had developed an interest in environmental justice and 'community-based participatory research'; exploring how local communities can play a role in asking and answering questions about the link between their local environment and health problems (Balshem 1993;Cornwall & Jewkes 1995;Leung *et al.* 2004;Metzler *et al.* 2003;O'Fallon & Dearry 2002;Schulz *et al.* 2002;Suarez-Balcazar *et al.* 2005). My interest was further developed through reading about similar movements in health areas such as HIV/AIDS, mental health and cancer, where patients have challenged, as well as worked alongside, the scientific and medical community to ensure that the research topics they prioritise are investigated (Brown *et al.* 2004;Brown & Zavestoski 2004;Epstein 1996;Klawiter 2008).

I applied for the research position in the SRP because I was keen to develop my interest in Health Social Movements (HSMs) (Brown & Zavestoski 2004) and in practical terms to gain first-hand experience of working with stroke survivors to address their own questions about their health concerns. The research position entailed evaluation of stroke survivor participation in two separate, but related, enterprises: developing new or improving existing services, in the case of the Transforming Stroke Services Project (TSSP); and researching stroke and stroke services, in the case of the Stroke Research Programme (SRP). Prior to taking up the position of research associate, I was unaware of specific government policies which encourage, and in some cases require, researchers and health care professionals (HCPs) to involve patients in research and service development. Moreover, I was unfamiliar with the terms employed by those promoting the policies such as ‘user involvement‘ and ‘patient and public involvement’ (or ‘PPI’), and the labelling of patients as ‘service users’ or ‘consumers’. This policy-driven, professionally-led form of patient participation provided an unexpected contrast to the grass roots or ‘community-led’ approaches I was familiar with.

This additionally meant that the field I was researching was not completely familiar to me as I had never worked before in the National Health Service (NHS), and had little knowledge about formal user involvement policies, and little awareness of and knowledge about stroke aside from a grandfather who had a series of strokes. Despite conducting ethnography ‘at home’, the setting I was working in, and the terms I was working with, were unfamiliar and ‘exotic’ (Van Maanen 1988: 14).

The questions investigated in this thesis concern the implementation of user involvement policy as it was put into practice in the two enterprises. The questions stem from the research project I was employed on to implement and evaluate stroke survivor participation in stroke service development and stroke research. My interest in community-academic partnerships, health social movements and patient activism, as well as the desire to critically analyse formal policies on patient participation, have further driven the thesis questions.

This chapter outlines the central issue and questions that the thesis will address and introduces the major concepts, policies and theories that will inform the thesis. First, I start with an overview of user involvement policy in health research and service development. I then discuss the rise of user involvement in the wider context of challenges to expert authority in arenas beyond that of public institutions specific to this thesis: universities and the National Health Service (NHS). Following that, I introduce the concepts of ‘power’ and ‘empowerment’. These terms feature heavily in the user involvement policy literature. My initial research questions arose from my acquaintance with this literature, particularly as user involvement policy was promoted with the intention to redistribute power from professionals to patients. I then introduce health social movement theory, in particular embodied health movement theory, as a form of patient participation which provides contrast to the professionally driven participation expressed in user involvement policy. Finally, I discuss user involvement policy in relation to stroke - the empirical health area under investigation - before providing an overview of the structure of the thesis with a chapter by chapter summary.

1.1. User involvement policy

The involvement of service users in the development and evaluation of health services and health research has been increasingly promoted internationally (National Institutes of Health 2012;WHO Regional Office for Europe 2002). The involvement of service users as partners in the health service has been a policy promoted by all nations within the United Kingdom (UK) over the last decade (Department of Health 2000;National Assembly for Wales 2001;Scottish Executive 2003).

Policy documents argue that involvement of service users improves the quality of health services through development of a more responsive service; it results in better outcomes of care and improved population health, reduces health inequalities, and fosters greater local ownership of health services and a better understanding of why and how local services need to change and develop (Farrell 2004). In the English NHS, the duty to consult and involve patients and the public in the planning and development of health services is a legal requirement (Health and Social Care Act 2001) although there is a raft of arrangements which fall under the umbrella of involvement: patient choice, patient surveys, Patient Advice and Liaison services, patient forums and networks, Overview and Scrutiny Committees, complaints procedures, and NHS Foundation Trust Boards (Department of Health 1999). To date, user involvement remains a policy priority within the NHS, with the most recent White paper emphasising the importance of patients' 'collective voice' and calling for greater engagement of patients in the health service (Department of Health 2010: 19).

As well as being encouraged to have a say in how services are developed, patients have been encouraged to participate in their own care through having a role in making decisions about personal health care and treatment plans. The Department of Health (DoH) has made a distinction between patient involvement – involvement of a patient in treatment decisions and individual care plans – and public involvement – involvement to influence the policies, plans and services of the NHS (Farrell 2004). In this thesis, I am primarily concerned with the latter definition: the involvement of patients and the public in decisions about health services, rather than patient involvement in individual treatment plans.

The DoH in England has made the involvement of patients and the public a priority in health research (Department of Health (Research and Development Directorate) 2006). Whilst in the UK the terms 'user involvement' or 'patient and public involvement' tend to be used, in North America parallel drives tend to be promoted using terms such as 'community-based participatory research' or 'participatory research'. The principles of community-based participatory research (CBPR) have been identified as being: participatory, cooperative, and empowering. CBPR engages community members and researchers in a joint process to which each contributes and co-learns equally and through which participants can increase control of their lives. CBPR involves systems development and local capacity building and achieves a balance between research and action (Israel *et al.* 1998;Minkler 2004). UK user involvement by contrast, has been less explicitly defined. The DoH states that it is good research practice that 'relevant service users and carers or their representative groups should be involved wherever possible in the design, conduct, analysis and reporting of research' (Department of Health 2005b: 8). More often, user involvement in research is defined in contrast to traditional research approaches which do not actively involve patients:

> By 'involvement' we mean: An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public (Involve 2007: 7).

Whilst it is not a legal requirement for researchers to involve patients, as it is in the health service, researchers are encouraged to state how patients will be involved in research in grant applications for funding and in the research governance process. Despite the lack of clarity about what involvement in research entails and the fact that there is no recognised measure of quality user involvement, UK policy documents claim that the active involvement of patients in research will enhance research quality through improving design and conduct of research and trials; facilitating recruitment and retention of research participants; increasing the relevance of research outcomes; improving dissemination and implementation of results; and increasing lay knowledge and fostering mutual education between users and professionals (Hanley *et al.* 2003;Oliver *et al.* 2004).

In England, user involvement in research has been promoted by the DoH for over a decade (Department of Health 1999;Department of Health 2005b; Department of Health (Research and Development Directorate)2006; Oliver *et al.* 2004).

Demonstrating their commitment to user involvement and to promote the practice amongst service users and researchers, the DoH established and funded Consumers in NHS Research in 1996 (Involve 2011). In 2001, the organisation extended its remit to include public health and social care research, and in 2003, changed its name to 'Involve: promoting public involvement in NHS, public health and social care research' (Involve 2011). For the purposes of this thesis, my definition of research includes the areas of health services research, clinical research, public health research and social care research.

When discussing or writing about user involvement in both the health service and research arenas, a number of terms are utilised to refer to the lay participants in the process. The terms 'service user', 'user', 'consumer', 'patient', and 'public' are used interchangeably to refer to recipients or potential recipients of health services. I shall use the term 'service user' throughout this thesis to refer to people who have used a health service, who are currently using a service or who are the unpaid carers of those who use or have used health services. However, it is important to acknowledge that some of these terms are contested. Some stroke survivors I met through the course of my fieldwork were bemused when they were referred to as 'service users', preferring to be called 'patients'. The term 'service user', along with 'consumer', is rejected by those who do not associate the health service with a market model. The term 'service user', or the shortened term 'user', is rejected by those who fear association with terms such as 'drug user'.

A variety of terms were used by those in the two enterprises where I conducted the research to refer to people who had had a stroke and their family members who cared for them. For example, clinicians would refer to people who had had a stroke as 'patients' even though the majority of those who had had a stroke involved in either of the two enterprises were no longer receiving stroke-related health services. NHS managers used the term 'service user' or 'carer'. Those from stroke-related charities and the voluntary sector referred to those who had had a stroke as 'stroke survivors' or 'people living with stroke'. This choice of terminology reflected the empowerment ethos upon which the organisations were run, and was a nod to the language adopted by established activist and survivor movements in the mental health and HIV/AIDS fields (Sweeney *et al.* 2009; ACT 2012). Whilst many people living with HIV/AIDS feel terms such as 'victim' and 'sufferer' imply they are powerless, with no control over their lives, the stroke survivors I met through the course of the research, tended to refer to themselves, and others in the same situation, as 'stroke victims' or 'stroke sufferers'. Some disliked the term 'survivor' as it denoted that they had survived the stroke and suggested that others had not. In the case of breast cancer activism, some women with breast cancer had chosen to reject the term 'breast cancer survivor' and reclaim the term 'victim', not because they were passive or fatalistic, but instead to draw attention to the existence of injustice surrounding the causes of breast cancer and the government response to the disease (Klawiter 2008). Whilst acknowledging that each term is morally loaded, for the purposes of simplicity I have chosen to use the term 'stroke survivor' to refer to those who have had a stroke and the relatives and friends who care for them.

Over the course of researching and writing this thesis, calls for evidence of the impact of user involvement have become more insistent. In a health service predicated on evidence-based practices, it is surprising that user involvement is promoted despite scant evidence of its impact. The published literature on user involvement primarily describes case studies involving service users in health service development or health research. For example, such studies describe how the projects were set up; how service users were recruited; the different roles undertaken by service users; and the outcomes of the project. However, a number of reviews report that there is little systematic evaluation of user involvement, with insufficient attention given to the evaluation of the impact of involvement (Boote *et al.* 2002;Crawford *et al.* 2002;Fudge, *et al.* 2007;Oliver *et al.* 2004;Simpson & House 2002).

Where ‘evidence’ of impact has been reported, this is mainly based on authors’ reflections on, or anecdotal stories about, implementing user involvement, and it is unclear how the reported outcomes of involvement were achieved. Where evaluation has been undertaken, the focus is primarily in terms of how to improve the processes and mechanisms to involve service users. More limited is the body of empirical research examining the purpose of user involvement, the wider context of involvement and how wider processes contribute to and have an influence on the outcomes of user involvement.

Tritter and McCallum (2005) and Thurston *et al.* (2005) argue that because there is no systematic way to evaluate user involvement, it makes it difficult to compare projects across different health areas and draw conclusions about the value of user involvement. In recent years, some authors have started to answer calls for systematic evaluation of user involvement. Morrow *et al.* (2010: 533) have developed a 'model of quality involvement' - a practical measure to help researchers and service users reflect on and evaluate user involvement activities. However, others have argued that studying the outcomes of user involvement alone obscures important dimensions of the phenomenon. Exploring these dimensions may reveal a better understanding of the value of user involvement (Contandriopoulos 2004;Mykhalovskiy & McCoy 2002).

A number of authors have commented on the lack of a precise definition of user involvement and that the aims of user involvement are multiple and go beyond improving healthcare (Contandriopoulos 2004;Florin & Dixon 2004;Fudge *et al.* 2008). In policy documents, user involvement is presented as a quality issue, attributed with the capability to make improvements to services. However, other analysts have explained the phenomenon of user involvement from a number of philosophical and political perspectives: consumerism, democracy and citizenship, and the rise of patient pressure groups (Harrison *et al.* 2002). The following section outlines some of the theories accounting for the rise of user involvement in the health service and in research.

1.2. Accounting for the rise of user involvement

Barnes and Prior have noted two trends in public services since the Thatcher and New Labour governments (Barnes & Prior 2009). The first trend is the utilisation of market models and the introduction of managerialism for organising public services. The second trend, and one that concerns this thesis, is the notion of governance: devolution of power from central state to public agencies, private sector interests, voluntary organisations, community groups and citizens (Barnes & Prior 2009). A number of theories have been put forward to explain the promotion of user involvement as part of health care reform, not only in the UK but throughout the developed world. These theories move beyond the premise that involvement of service users is simply a quality issue, encouraged in order to improve the design and delivery of services to better meet the needs of those who use them.

The rise in user involvement can be seen as a result of global, societal changes since the 1970s where it has become acceptable to question scientific and expert authority (Cowden & Singh 2007). In health care, this is particularly relevant in light of a series of health 'scandals'. The Tuskegee Syphilis Study (1932-72) studied, but did not treat, African-American men with syphilis, long after a definitive cure for syphilis had been discovered (Jones 1981). In the 1980s and 1990s, NHS hospitals, and in particular the Bristol Royal Infirmary and Alder Hey Children's Hospital, were involved in a health service and research scandal which challenged the moral authority of professionals (Lawrence 2002). During an inquiry into high mortality rates in paediatric heart surgery at the Bristol Royal Infirmary, a professor disclosed to the investigation panel that children's hearts and other organs were stored at Liverpool's Alder Hey Hospital and other hospitals for research purposes to improve the results of paediatric cardiac surgery. The subsequent inquiry at Alder Hey revealed the widespread practice of the removal and retention of patients' organs for research purposes without proper research ethic committee approvals or the consent of patients' next of kin (Hall 2001;Lawrence 2002). More recently in 2006, Northwick Park, an NHS hospital, was hit by a research scandal. Six men were admitted to intensive care at the hospital after suffering severe reactions whilst taking part in a phase one clinical trial of an experimental drug in a research unit run at the hospital by a contract research company. In both these cases local and national press seized on these accounts, presenting them as a 'scandal'. The resultant media coverage constructed a narrative in which science and scientists were out of control, the quest for scientific knowledge overshadowed public safety, and innocent and vulnerable members of the public were coerced into taking part in irresponsibly conducted research (Stobbart *et al.* 2007). One reading of user involvement, therefore, is as a form of participatory governance to monitor research and reinstate trust in health services and research.

Another reading situates user involvement in a wider context of citizen engagement in other public spheres of life where 'getting involved' is the mark of an active and responsible citizen. For example, in journalism, consumers of the news are frequently asked to send in their photographs, eye witness reports, or comments relating to a news story, and internet sites such as Wikipedia harness the power of the individual to aggregate knowledge rather than this being the role of institutions (Leadbeater 2008;Shirky 2008). In the context of health service development and health research the 'experiential' knowledge of patients (Caron-Flinterman *et al.* 2005) is valued as it is seen to bring something new to the table, a form of knowledge which professionals cannot provide. Involvement in health research and service development therefore goes hand in hand with other government initiatives to encourage active and socially responsible citizens and overcome the democratic deficit (Citizenship Foundation 2004;Newman *et al.* 2004).

Much of the user involvement literature takes the basic premise that it is right to open up decision-making in research and service development to the people that are directly affected by research outcomes and services. Involvement can be seen as a means of giving people a 'voice' (Farrell 2004;Hanley *et al.* 2003). As health services and research in the UK are primarily funded by tax-payers, it is argued that people who contribute to taxes have a right to say how this money should be spent. In the face of health service economic costs, the involvement of service users in health service development and health research can further be seen as promoting individual responsibility for health, linked to movements such as self-help groups and the Expert Patient[1] (Wilson 2001).

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[1] The Expert Patient is a policy initiative to encourage patients with a long term medical condition to attend a training programme to learn how to self-manage their condition.

Some authors have argued that involvement is a way for those in positions of authority to reinforce existing institutionally defined power relations and to legitimise decision-making (Contandriopoulos 2004;Hodge 2005;Walker & Jacobs 2002). Support for unpopular decisions can be achieved through consultation with service users, even though the consultation terms may be biased towards the government's opinion and there is no requirement for those leading the consultation to act on the views given by participants. Harrison and Mort (1998) characterise public and user involvement as a 'technology of legitimation' to which particular professional groups accord no intrinsic representative legitimacy, but which they use to advance their own ambitions over those of other groups.

Readings of what user involvement 'really' is are therefore multiple. Understanding the rise of user involvement and what is driving the policy imperative to involve service users may be revealed through ethnographic inquiry into how these policies are interpreted and implemented by the various actors within health service and research contexts. In the following section, I focus specifically on UK user involvement policy and two concepts contained within the policy: power and empowerment.

1.3. Power and empowerment in user involvement policy

In the *Anthropology of Policy*, Hansen remarks that the study of a policy is 'inseparable from issues of power' (1997: 89). A striking number of references are made to power and empowerment in DoH policy documents concerning the involvement of patients in the NHS and health research. Under Labour governments of Blair and Brown, policy documents argue that a fundamental change is required in the relationship between those in authority and the public, in particular transferring power from the clinician to the patient (Department of Health 2001c;Department of Health 2005a). The empowerment of patients is cited as one of the goals of NHS improvements and a means for patients to improve their health through choice and control over health decisions (Department of Health 2005a). Policy documents suggest that the involvement of patients and the public in developing services will assist in this shift of power and empower patients (Department of Health & Patient and Public Involvement Team 2006). At the time of fieldwork, the DoH stated that it is committed to ‘empowering citizens to give them more confidence and more opportunities to influence public services’ and forms part of a ‘wider government commitment to revitalise community empowerment and engagement across the broad range of public services’ (Department of Health & Patient and Public Involvement Team 2006: 3).

In policy documents, empowerment has been conceptualised not only as a pre-requisite to involvement (patients needing to be empowered before they can engage with professionals) but as an outcome of involvement. Farrell’s (2004) review of the evidence for implementing the policy of patient and public involvement (PPI) lists the empowering outcomes of involvement for patients as personal growth, increased confidence and self-perception, reduction in anxiety and fear, greater knowledge of health conditions and greater control over their own lives and health conditions. As

Cheek (2003) notes, in much of the writing about partnerships in health care, it is the patient who is to be empowered by the health professional and not the health professional by the patient.

While less explicit than the health service literature, the language and rhetoric used in policy documents relating to user involvement in health research take a similar approach towards power and empowerment. The empowerment of service users is promoted as one of the benefits of involving service users in research (Royle *et al.* 2001).

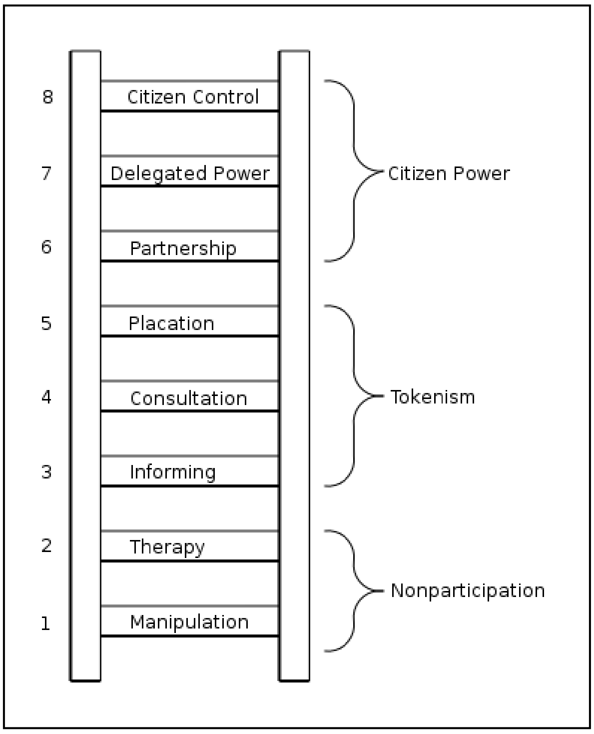
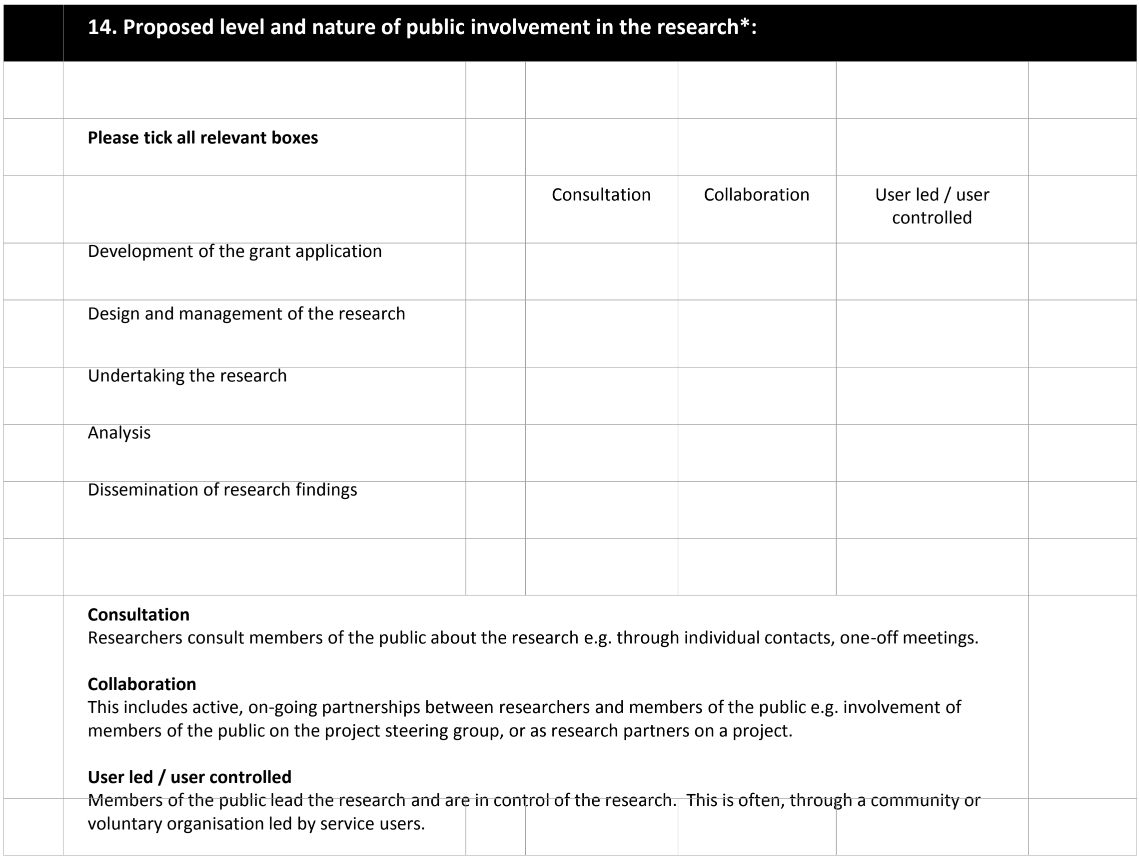


Figure 1.1 Arnstein's ladder of participation (Arnstein 1969)

Those promoting user involvement in research have tended to use a model of participation based on Arnstein’s ladder of citizen participation developed in the late 1960s (see Figure 1.1 above). Arnstein (1969) developed the model in the context of urban redevelopment in response to the growing civil rights movement, but believed the model was more broadly relevant. Participation is seen as a proxy for power, and the model identifies levels of citizen power or control according to the degree of involvement or participation. The first two rungs ‘Manipulation’ and ‘Therapy’ are labelled non-participation because, whilst citizen participation is invited, it is used to ‘educate’ or encourage citizens to think differently. The next three rungs labelled ‘Informing’, ‘Consultation’ and ‘Placation’ are termed tokenistic participation, because whilst citizens are consulted they ultimately lack the power to challenge the status quo. The final three rungs represent citizen power, as it is here, Arnstein argues, that citizens have control over decision-making (Arnstein 1969).

The model has been loosely, but not explicitly, adapted by the DoH and research funding bodies to define user involvement in applications for research funding. In the case of DoH funding, researchers are asked to provide details of public involvement in their proposed research, and categorise the extent of public involvement according to whether it is consultation, collaboration or user-led/user controlled. Figure 1.2 shows how Arnstein’s ladder has been adapted to guide applicants for National Institute for Health Research (NIHR) funding to describe how they intend to involve service users in their research.



14. Proposed level and nature of public involvement in the research*:

Please tick all relevant boxes

	Consultation	Collaboration	User led / user controlled
Development of the grant application			
Design and management of the research			
Undertaking the research			
Analysis			
Dissemination of research findings			

Consultation
Researchers consult members of the public about the research e.g. through individual contacts, one-off meetings.

Collaboration
This includes active, on-going partnerships between researchers and members of the public e.g. involvement of members of the public on the project steering group, or as research partners on a project.

User led / user controlled
Members of the public lead the research and are in control of the research. This is often, through a community or voluntary organisation led by service users.

Figure 1.2 Extract from NIHR research funding application form

By defining user involvement according to Arnstein’s ladder of participation, a similar hierarchy of different forms of involvement is implied: consultation with service users in research, located at the lower rungs of the ladder, results in limited power for service users. User-led or user controlled involvement in research, located in the upper rungs gives the greatest degree of control to service users, with the implication that this is the most desired form of involvement.

Arnstein’s model and its use by promoters of involvement has been criticised by some on the grounds that it presents the power of users to act in formal decision-making processes as a single dimension without taking into account the different forms of and justifications for involvement (Morrow *et al.* 2010;Tritter & McCallum 2005). Tritter and McCallum state that ‘user engagement and empowerment are complex phenomena through which individuals formulate meanings and actions that reflect their desired degree of participation in individual and societal decision-making processes’ (Tritter & McCallum 2005: 157). Furthermore, the model assumes that higher levels of control equate to better involvement (Morrow *et al.* 2010).

Whilst little clarity is provided in policy documents about what involvement should entail, what is more ambiguous is how the transfer of power from professionals to patients should be achieved. There is therefore a need to understand, through empirical research, the relationship between user involvement, power and empowerment. In their book *Anthropology of Policy*, Shore and Wright take a Foucauldian stance to investigate how policies construct their subjects as objects of power and ask what new kinds of subjectivity or identity are created in the modern world (Shore & Wright 1997: 3). Central to this thesis is the question– what happens when user involvement policy is implemented? This includes an attempt to understand how the identities of researcher, patient, health care professional, and service user are created through the implementation of the policy.

1.4. Social movements in health

Whilst my empirical data relate to user involvement as a relatively recent form of patient participation primarily led by professionals, these data can be seen in the broader context of HSMs, examples of movements of citizens who organise to improve health care for specific conditions. HSMs have been defined as ‘collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organisations, supporters, networks of cooperation, and media’ (Brown *et al.* 2004: 52). HSMs are an important political force concerning health access, quality of care and broader social change. Brown *et al.* associate HSMs with recent trends towards ethical concerns regarding the conduct of scientific research, disillusionment with medical and scientific expertise as *the* authority on pressing health concerns, and the empowerment of patients and encouragement of their active participation in health care (Brown *et al.* 2004).

Brown *et al.* (2004) developed a typology of HSMs, divided into three ideal, but overlapping, types of health social movement (see Figure 1.3). The range of organisations will not fit neatly within one type but will overlap into one or more categories. For example, Brown *et al.* cite the women’s health movement as a constituency based movement with elements of health access movements (seeking health services specifically aimed at women) and embodied health movements (challenging assumptions about psychiatric diagnoses for premenstrual symptoms) (Brown *et al.*2004).

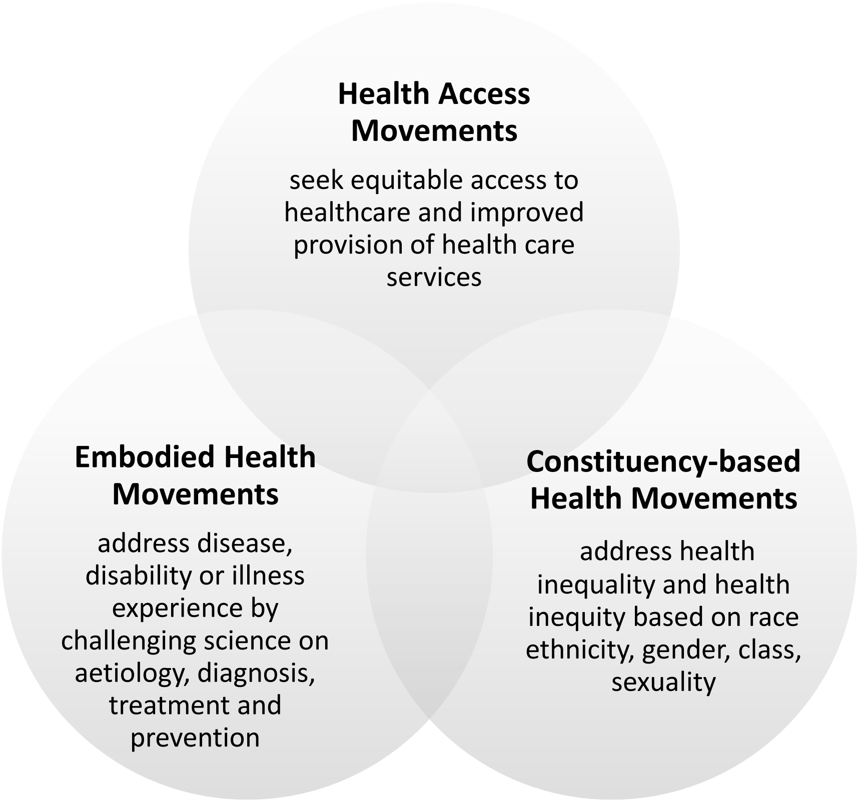


Figure 1.3 Typology of Health Social Movements (adapted from Brown *et al.* 2004)

Brown *et al.* (2004) term the most recent form of HSM Embodied Health Movements (EHMs), defined as organised efforts to challenge knowledge and practice concerning the aetiology, treatment and prevention of disease incorporating personal understanding and experience of the illness. They associate EHMs with the recent trend towards the empowerment of patients and more active involvement in their health care. EHMs are defined by three characteristics: (1) incorporating the biological body within social movements; (2) challenging existing medical/scientific knowledge and practice based on intimate, first-hand knowledge of participants' bodies; (3) activists collaborating with scientists and health care professionals to pursue treatment, prevention, research, and funding (Brown *et al.* 2004). As with other social movements, EHMs depend on the emergence of a collective identity and in some cases grievance as a mobilising force (Brown *et al*. 2004). Examples of EHMs and health fields where there has been strong activism by and mobilisation of patients are HIV/AIDS, cancer, mental health and environmental health. Perhaps with the exception of environmental health, these health domains are similarly ones where in the UK user involvement has a longer history.

User involvement practices or activities, like EHMs, are usually defined by a particular illness or disease. Often those service users involved have been driven to participate due to dissatisfaction with health services and treatment options; particularly this is the case for mental health service user involvement (Beresford & Branfield 2006). Applying EHM theory to professionally driven forms of participation such as user involvement raises a number of questions. How does EHM theory fit with movements which have been promoted, established and led by professionals rather than patients? Authors such as Allsop *et al.* (2004) argue that a condition draws people into social movements because they feel marginalised by dominant social practices, but what happens when it is professionals who are drawing patients of a similar condition together as is the case with user involvement - a policy driven, professionally led form of participation? Furthermore, how do we understand cases where a tradition of patient mobilisation is minimal, such as is the case with stroke?

1.5. The case of stroke

Empirically, the research conducted for this thesis focuses on the case of stroke. A stroke occurs suddenly, when the blood supply to the brain is stopped or restricted, causing brain damage and in most cases death or disability. An ischaemic stroke (the most common type, accounting for over 80% of all strokes) occurs when the blood supply to the brain is stopped due to a blood clot. A haemorrhagic stroke occurs when a weakened blood vessel supplying the brain bursts, flooding part of the brain with blood, damaging brain cells (Rudd, Irwin, & Penhale 2005). Worldwide, stroke is a leading cause of disability (World Health Organisation 2003). In England, stroke is one of the leading causes of death after heart disease and cancers (National Audit Office 2005), and is the leading cause of adult disability (Wolfe 2000) with at least 300,000 people living with moderate to severe disability as a result of having a stroke (National Audit Office 2005). In terms of development of health care interventions, policy and research, stroke has been described as a 'Cinderella' disease, the poor relative of other chronic diseases such as heart disease (Wolfe *et al.* 2001; Pendlebury 2004).

Compared to other health areas, such as HIV/AIDS, cancer and mental health, user involvement in the field of stroke has been largely underdeveloped. A search of the UK published literature up to January 2011 identified four articles describing the involvement of stroke survivors in research (Ali *et al.* 2006;Koops & Lindley 2002;Morgan *et al.* 2005;Robinson *et al.* 2005), and two studies describing the involvement of stroke survivors and informal carers in priority setting for stroke services (Chappel *et al.* 2001;Jones *et al.* 2008)[2]. A search of the grey literature, using Internet search engines and a database of research projects involving service users maintained by Involve, produced a few further examples of user involvement in stroke services[3] and stroke research[4].

In all the cases identified, the involvement of stroke survivors was initiated by professionals and was driven in part by professionals' need to meet policy requirements to involve service users in both research and service development. In the examples cited above, there was not one case of stroke patients 'demanding a say' in how services are shaped or organising themselves into activist grass roots movements, as has occurred in other health areas such as HIV/AIDS, breast cancer and mental health (Altman 1993;Brown *et al.* 2004;Brown & Zavestoski 2004;Epstein 1996;Tomes 2006). This is despite a number of 'grievances' which could galvanise and mobilise stroke survivors to press for better outcomes for stroke patients:

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[2] These articles are in addition to two published articles stemming from this research – see Appendix XIII.

[3] Patient and carer recommendations of topics to be addressed by Royal College of Physicians Clinical Guidelines for Stroke; Improving information for stroke patients and carers (Weston Area Health NHS Trust, Bedford Hospitals NHS Trust); Keeping carers and patients better informed on treatment and care (Bedford Hospitals NHS Trust); Developing stroke services (Bedford Hospitals NHS Trust, Tower Hamlets Primary Care Trust, Mid Yorkshire Hospitals NHS Trust); Improving food and nutrition for stroke patients in hospital (Winchester and Eastleigh Healthcare Trust).

[4] Bryan, K. Work after Stroke; Bowen, A. The ACT NoW Study: Assessing Communication Therapy in the North West.

- the significant impact stroke has on patients and family members who care for them (Low *et al.* 1999;Wolfe 2000);
- inequalities in who has a stroke – the burden being disproportionately carried by those from lower socio-economic status and black minority ethnic groups (Cox *et al.* 2006;Wolfe *et al.* 2002)
- the long history of poor quality stroke services in the UK (King's Fund 1988;National Audit Office 2005); and
- considerable worldwide underfunding of stroke research compared to health areas such as coronary heart disease and cancer (Pendlebury 2007).

Stroke makes a theoretically interesting case-study for user involvement as characteristics of the illness are perhaps indicative of why historically user involvement has been less extensively implemented with this patient group compared to other patient groups. Guidance on user involvement suggests that a number of groups of people who are marginalized are likely to be excluded from involvement activities (Hanley & Staley 2005). Those who have a stroke are likely to fall into three of these categories – older people, people from black and minority ethnic groups and disabled people. Stroke tends to affect older people, with the incidence of stroke doubling with each successive decade over the age of 55 years (Wolfe 2000). The disabilities and psychological problems caused by stroke may impede stroke survivors' participation in involvement activities. It has been argued that older people are less consumer-oriented than younger people and lack the skills to participate (Bentley 2003). A low priority has been afforded to involving older people in the planning and development of health services (Healthcare Commission 2006). This is despite policy recommendations that older people's views and the views of those with experience of stroke need to be included in plans for service development and evaluations of services (Department of Health 2001a;Intercollegiate Stroke Working Party 2004).

The research undertaken in this thesis therefore will focus on implementation of a policy within a context with a limited tradition of participation both in terms of formal, policy-led involvement and grassroots, patient-led activism. Having summarised the policy and theoretical context of user involvement, in the final section of this chapter, I outline the structure and organisation of the remaining chapters of the thesis.

1.6. Aims, objectives and organisation of the thesis

Using stroke as an example, this thesis investigates the implementation of the policy to involve service users in health research and health service development. There are three core objectives:

- To explore how concepts of power and empowerment are defined and operationalised in the user involvement literature.
- To investigate how user involvement policy was put into practice in the two enterprises by the professionals charged with implementing it and how stroke survivors invited to participate respond.
- To understand why stroke survivors have been less mobilised as a patient group compared to other patient groups and why a stroke embodied health movement has not developed.

Chapter 2 of this thesis presents a concept analysis of the terms power and empowerment through a literature review of peer reviewed published articles concerning user involvement. The aim of the review is to explore how authors define and conceptualise the two terms central to much of the user involvement policy literature.

Chapter 3 completes the background to the thesis with a discussion of two theoretical frameworks used in the thesis. I make the case for applying Lukes’ three-dimensional view of power and the concepts of biosociality and biological citizenship to the exploration of user involvement in health service development and health research.

Chapter 4 outlines the ethnographically informed methods I used to carry out the empirical research. I start the chapter by discussing the rise of anthropology and the ethnographic approach in public health and health services research and the justification for taking the ethnographic approach in this thesis. I then discuss how I collected the data through participant observation and interviews and how I analysed the body of resulting data (fieldnotes, interview transcripts, documents, and quantitative data). Finally, in this chapter I discuss some of the methodological and ethical challenges to data collection and analysis.

Chapter 5 presents a description of the geographical location, the local community and the two settings where I conducted the research. I introduce the notion of 'multi-sited ethnography' and its relevance to this study. The study field was not discrete and bounded; the sites of research being the policy context at an international and national level, interpretations of the policy within the two settings and the interactions between professionals and patients through the course of policy implementation.

Chapters 6 and **7** are based on the ethnographic data collected through participant observation. Chapter 6 focuses on the implementation of user involvement policy in an NHS setting to improve stroke services in two boroughs of south London. Chapter 7 focuses on implementation of user involvement policy in an academic research setting.

After examining how the policy was implemented in the two different settings, in **Chapter 8,** I bring together the findings to explore the question of why stroke activism has not developed compared to other health conditions. I bring together Lukes' three-dimensional view of power, biological citizenship and Health Social Movement theory to critique user involvement policy.

Finally, in the closing chapter, **Chapter 9,** I bring together the conclusions of my research and suggest avenues for further research developments.

Chapter 2: A critical review of the concepts of power and empowerment in the user involvement literature

Concepts of power, and more recently empowerment, have long been discussed in the context of health and illness and, in particular, the relationships between patients and healers. Parsons' (1951) work on the sick role in the early 1950s became one of the most influential concepts in medical sociology. The sick role described doctors as having the knowledge and authority to legitimise an individual's illness and consequently their role as a patient (Parsons 1951). Sociological study of the medical profession in the west suggests that the use of medical, expert knowledge has enabled the medical profession to extend its dominance and monopoly over patients (Morgan *et al*. 1985). A number of authors have commented on how ill-defined the term 'empowerment' is and have argued that clarification of what is meant by empowerment is needed (Anderson 1996;Hagner & Marrone 1995;Perkins 1995). Perkins (1995) calls for an examination of the term 'empowerment', given its prolific and unquestioned use in public policy and social interventions.

As I argued in Chapter 1, power and empowerment have been readily discussed in the context of user involvement, with policy documents suggesting that involvement of patients and the public in developing services will assist in the empowerment of patients and the transfer of power from professionals to patients (Department of Health & Patient and Public Involvement Team 2006). In UK policy documents on user involvement, empowerment has been conceptualised as both an outcome of involvement (the process of being involved empowers service users) and as a pre-requisite for involvement (service users need to be empowered prior to involvement so that they can challenge professionals). However, policy documents provide little detail regarding how user involvement practices will empower patients and scant evidence that patient empowerment, as an outcome of involvement, is being achieved.

The fact that such highly contested and ill-defined concepts feature prominently in policy documents and discussions of user involvement prompted my investigation into the range and nature of understanding of the terms ‘power’ and ‘empowerment’. In order to locate my research in the existing body of literature I consider in this chapter how authors, evaluating or implementing user involvement activities, have defined and discussed power and empowerment. First, I outline the methods used in the review and present an overview of the papers selected for the review. Following this, I discuss in more detail aspects of the papers which help to answer the following questions: how authors conceive power and empowerment in relation to user involvement and how empirical examples of involvement relate to the policy aims of involvement.

2.1. Systematic search and narrative synthesis

The approach I took to identify and critically appraise the user involvement literature concerning power and empowerment is outlined below, followed by the results of the literature search.

Aim and overview of methods

My aim in this review of the concepts of power and empowerment in the user involvement literature is two-fold:

- to explore how authors interpret and understand the concepts of power and empowerment
- to relate the findings from empirical examples of involvement to the policy aims of user involvement.

I undertook a systematic search to identify relevant papers to include in the review. I then performed a narrative synthesis to critically appraise the publications and draw conclusions about the two concepts. The approach I took to identify the relevant literature is outlined below.

Search strategy

I conducted a literature search of English language papers published up until the end of February 2011 using three online databases (Science Citation Index Expanded, Social Sciences Citation Index and Arts & Humanities Citation Index) via the Web of Science. Table 2.1, overleaf, outlines the search terms I used. This consisted of a combination of free text and thesaurus terms for the main concepts: power and empowerment, and involvement and participation in health service development or health research.

Table 2.1 Search terms

Concept	Search terms
power, empowerment	power OR empowerment OR “power relations” [MeSH] OR control
involvement and participation in health service development or health research	user involvement OR patient involvement OR public involvement OR consumer involvement OR service-user involvement OR consumer* OR service-user OR citizen participation OR patient participation OR public participation OR community participation OR citizen engagement OR partnership OR lay OR research partnership OR participatory research OR collaborative research OR popular epidemiology OR participatory action research OR community-based participatory research

All papers identified through the electronic search were imported into a reference management software package (Reference Manager 11), where duplicates were removed. The titles and abstracts of the publications were read to decide if the paper met the inclusion and exclusion criteria (see below). Publications which appeared to meet the inclusion criteria after this initial assessment were then read in full to see if inclusion criteria were still applicable.

I undertook a hand search to identify further relevant material. I searched the bibliographic references of the full-text papers included in the review and key journals. I decided against undertaking a search of the grey literature to include book chapters and reports as there was a sufficient volume of literature and detail provided via peer-reviewed journals.

Inclusion and exclusion criteria

Studies were included if they discussed the involvement of service users in at least one stage of the health research process (commissioning, prioritising, designing, conducting or disseminating research (Buckland *et al.* 2007)) or in health service development. I did not limit the inclusion criteria according to the type of healthcare or disease group discussed. Studies published in English in peer reviewed journals were eligible for inclusion. Solely theoretical papers and papers that discussed the involvement of patients in shared decision-making about personal treatment and care decisions were excluded along with editorials, abstracts and letters. I excluded papers which discussed the involvement of patients and the public in health policy and health promotion. While there is an extensive literature relating to health policy and health promotion, which could be relevant to the thesis, I decided to keep this review focused to the settings for my research: health service development and health research.

Analysis

I used a narrative synthesis framework to synthesise and analyse the findings of the literature review (Mays *et al.* 2005). This approach follows an inductive mode of inquiry and focuses on process factors as well as outcomes in order to try and understand more about the nature of the phenomenon under investigation (Forbes & Griffiths 2002).This entailed a synthesis of the data to describe the data thematically, explore relationships in the data, and pool together the findings of studies to present an overview of the collected material.

A structured assessment of each paper was then undertaken to identify: the health area within which involvement was taking place; the type of involvement activity; whether the involvement of service users had been evaluated and whether this was an internal or external evaluation; how power and empowerment were discussed and defined by the authors and examples of how power and empowerment were operationalised within the involvement activity. Extracted data were entered into an Excel database set up with fields to record the required information.

I did not use a quality checklist to determine which papers should be included in the review. Whilst this is the usual method for systematic reviews, the approach was not applicable given that there is no agreed definition of quality in service user involvement. Papers which had used a poor quality methodology to evaluate user involvement were not excluded, as my primary interest in this review was how authors had discussed or defined power and empowerment. I made note of authors' roles in implementing or taking part in user involvement activities in addition to authoring the paper.

The extracted findings of the identified studies were synthesized in two ways. First, I tabulated the data to summarise the core details of the papers: country of origin, health service development or health research, and health service and disease domains. Second, I conducted a thematic synthesis according to whether each paper discussed empowerment, power, or both concepts. Recurring themes within each category were then identified, for example, a number of papers described mechanisms within participation initiatives in which 'power' remained with professionals.

Results

4165 publications were identified through the database search. 3916 publications were excluded based on reading the title and abstract because they did not discuss the involvement of patients or the public in health service development or health research. 249 publications were read in full to see if they met inclusion criteria. Of these, 89 publications met the review inclusion criteria. Ten further publications meeting the inclusion criteria were identified through hand searching. Ninety-nine publications were included in the review (see Figure 2.1).

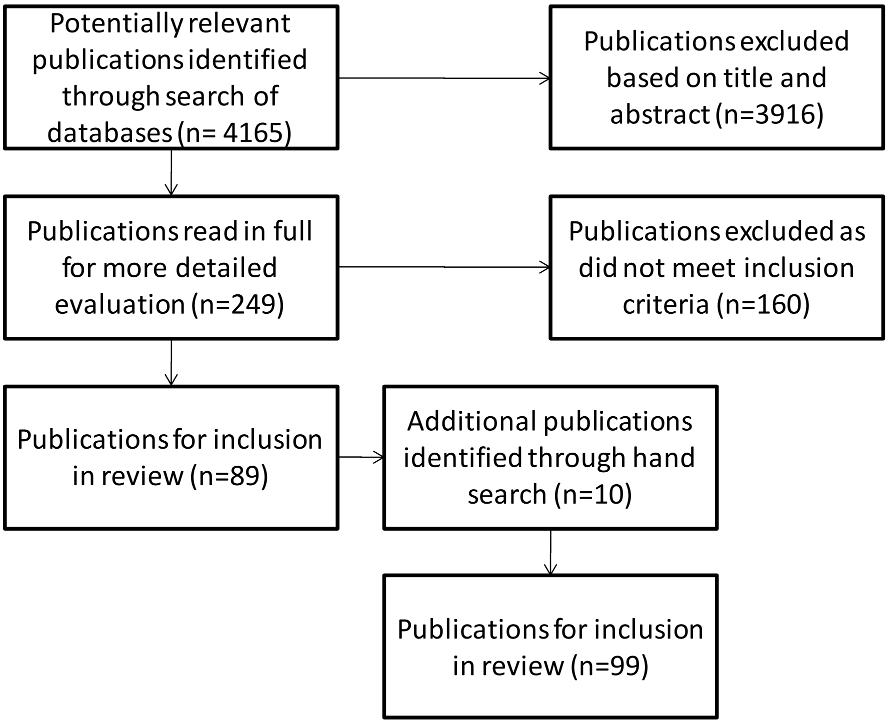

Figure 2.1 Flow chart of systematic search

Overview of included studies

Of the 99 publications included in the review, 48 papers described the involvement of service users in developing health services and 51 papers described the involvement of service users in health research. The majority of papers originated in the UK (n=34), United States of America (USA) (n=29), and Canada (n=20). A number of terms were used to describe participation activities: community-based participatory research (CBPR), participatory action research (PAR), collaborative research, user involvement. Papers originating in North America tended to use CBPR approaches whereas papers originating in the UK described participation of patients in either health service development or research as 'user involvement'. The majority of papers (n=31) referred to mental health, primary health care services (n=11), HIV/AIDS (n=9) and cancer (n=9). Table 2.2, overleaf, categorises the reviewed publications according to involvement in health service development or research and the corresponding health areas and country of origin.

Table 2.2 Overview of included studies

	County of origin	Health domains
User involvement in health service development (n= 48)	UK (n=24) USA (n=10) Canada (n=8) New Zealand (n=2) Australia (n=1) Mexico (n=1) South Africa (n=1) Tanzania (n=1)	Mental health (n=20) Primary health care (n=11) Health services – general (n=7) Cancer (n=3) HIV/AIDS (n=3) Drug abuse (n=1) Health services – homeless (n=1) Older people's health (n=1) Refugee health relief services (n=1)
User involvement in health research (n = 51)	USA (n=19) Canada (n=12) UK (n=10) Australia (n=2) Brazil (n=1) France (n=1) Ireland (n=1) Norway (n=1) Pakistan (n=1) South Africa (n=1) The Netherlands (n=1) One paper compared projects in two countries: USA & Bosnia-Herzegovina	Mental health (n=11) Cancer (n=5) HIV/AIDS (n=6) Environment and health (n=5) Older people's health (n=3) Indigenous health needs (n=2) Maternal and child health (n=2) Public health (n=2) Rheumatoid arthritis (n=2) Women's health (n=2) Children's refugee health services (n=1) Diabetes (n=1) Disability Health Needs Assessment (n=1) Disaster public health (n=1) Domestic violence (n=1) Drug abuse (n=1) Health services – general (n=1) Health needs - deaf people (n=1) Kidney disease (n=1) Neuromuscular diseases (n=1) Sexual health (n=1)

The majority of papers reported some form of evaluation of the user involvement activity. Primarily this was conducted by an external research team using research methods such as interviews, observation, analysis of documentary evidence, and focus groups (for example papers by Hodge 2005;Martin 2008;Mayo & Tsey 2009;Rabeharisoa 2003;Rutter *et al.* 2004). Other authors undertook a historical analysis of health services in a particular setting (Elliott 1996) or used survey methods (Tanaka *et al.* 2004). A minority of papers were written by health service providers or researchers responsible for implementing user involvement programmes or activities, with authors providing their reflections on user involvement, without detailing explicit evaluation methods (Carney *et al.* 2006;Freedman 2006;Malone *et al.* 2006;Thomas *et al.* 2001).

2.2. Concepts of power

In this section, I first discuss how the authors of the reviewed papers conceptualised power; whether they used any theoretical frameworks to define power and to ground their findings. Second, I report how power operated in the examples of patient involvement in service development and research included in the review according to the following themes: mechanisms to retain power with professionals, hierarchies of power within professional groupings, and hierarchies of power within patient groupings.

Defining power

The user involvement policy literature tends to characterise the relationship between professionals (clinicians and researchers) and patients as one of subordination. The assumption inherent in the policy literature is that through the involvement of service users in service development or research, this unequal relationship will be challenged and transformed. The majority of papers reviewed took this approach to characterise the relationship between health care professionals and service users, some even adopting the language used in policy documents. For example, in their evaluation of user involvement in a university diabetes research programme, Lindenmeyer *et al.* (2007) make the claim that a 'partial shift of power from researchers to users' occurred (Lindenmeyer *et al.* 2007: 268) echoing phrasing in Department of Health (DoH) policy documents on user involvement (for example see Department of Health 2001c). However, from the limited evidence provided (extracts from interviews with researcher and service user members of a diabetes research advisory group), it is hard to see exactly how this partial shift of power occurred. Furthermore, the authors adopt an unsophisticated reading of power as an entity which can be transferred from one person or group to another.

Hopkins and Niemiec's (2006) paper on the involvement of mental health service users in research typifies the stance that many of the reviewed papers took when discussing power relations between health service providers and service users. Hopkins and Niemiec, both mental health care clinical researchers, frequently used the term 'power', stating that service users, particularly mental health service users, are subordinate to health care providers and that 'ownership and power over the [research] process needs to remain … with users of the service' (Hopkins & Niemiec 2006: 42). However, they make no reference to theoretical frameworks to help ground their characterisation of power nor do they define power. At the end of the paper, they offer a definition of power as ‘productive, increasing exponentially’ once control over it has been relinquished by those who have traditionally been seen as the empowered group – health care professionals (Hopkins & Niemiec 2006: 45). This view differs from the concept of power as finite and which needs to be shared, which the policy literature tends to take. However, it is not clear how the authors came to this conclusion and whether the process of involving service users in research led them to this characterisation of power. The majority of other papers included in the review failed to ground theoretically the characterisation of the power relationship between professionals and patients (for example, see Lindenmeyer, *et al.* 2007;Norris *et al.* 2007;Thomas *et al.* 2001). A minority of papers adopted a particular theoretical stance regarding power. These papers and the corresponding theoretical frameworks are presented in Table 2.3. Ponic *et al.* (2010) were the only authors to call for a deepening of theoretical perspectives to inform participatory research. They argue that undertheorising the consequences of power imbalances between researchers and patients leads to an assumption that partnerships in health research are ‘good’.

Table 2.3 Publications adopting a particular theoretical stance regarding power

Publication	Theoretical framework
Lloyd *et al.* 1996	Lloyd *et al.* applied a *disability emancipatory research* framework to reflect on a research project the authors were involved in to design a survey with disabled people to investigate their needs. A disability emancipatory approach closely links research to policy-making structures to influence outcomes. This approach questions whether the research will result in material improvements in the quality of life of disabled people. Within this paradigm a transfer of power is required; either 'won' by service users through strategic action or 'given away' voluntarily by those in established positions of power.
Hodge 2005	Hodge investigates the power dynamics at work in a user involvement mental health initiative using Habermas' theory of *communicative rationality* or *communicative ideal.* The democratic potential of the communicative ideal equates the voices of everyday life and experience (subjective knowledge) to those of specialism and expertise (objective knowledge). However, the presence of power can distort communication, placing barriers which excludes certain voices, gives legitimacy to the status quo and reinforces existing structural power inequalities between service users and professionals.
Rabeharisoa 2003	Whilst Rabeharisoa does not explicitly define power, she locates power in one of two models pertaining to patient organisations' involvement in research. The *auxiliary model* where patients align themselves to professionals; and the *emancipatory model* where expertise in a disease is founded on patient experience. In the *emancipatory model,* patients assert their collective identity to challenge the monopoly held by professionals.
Ponic *et al.* 2010;Salmon *et al.* 2010	Both sets of authors apply feminist theory to participatory action research with groups of women. Taking a feminist perspective, power is viewed as a generative resource to be redistributed. In the case of participation in research, Ponic *et al.* argue that power-with approaches are needed to realise the potential of participatory research. Power-with means finding ways to share power that are cumulative and expansive, as opposed to traditional power-over approaches where someone controls, dominates, and imposes their will on others.
Doyle & Timonen 2010;Malone, *et al.* 2006	Both sets of authors conducted Community Based Participatory Research with the emphasis on power sharing (between university researchers and the community) and the empowerment of the community through research and action. They made reference to the work of Paulo Freire who sought to question and realign accepted power imbalances by emphasizing egalitarian relationships and focusing on empowerment through education of the disadvantaged and oppressed.

How power remains with professionals

Despite policy assertions that user involvement is a mechanism for service users to challenge professional dominance, a number of papers stated that implementing user involvement failed to transform the traditional relationship between professionals and service users (Anderson *et al.* 2006;Bowl 1996;Callaghan & Wistow 2006a;Callaghan & Wistow 2006b;Hodge 2005;Milewa *et al.* 1998;Poulton 1999;Rutter *et al.* 2004). Traditional relationships, such as service users being subordinate to clinicians, were upheld, with service users unable to challenge these relationships despite government rhetoric on the new approach to developing services (Anderson *et al.* 2006;Callaghan & Wistow 2006a;Callaghan & Wistow 2006b;Hodge 2005). These papers identified a number of ways which led to this failure to transfer power.

Formal versus lay-led forms of participation

A clear conclusion made by a number of authors' evaluations of involvement was that formal, professionally initiated user involvement diminished the power of service users, and kept power with professionals (Elliott 1996;Hodge 2005;Roy & Cain 2001). Elliot (1996) describes how mental health advocacy groups were subsumed into formal roles as employees or appointees on regional health boards, losing their independence and influence to object to state actions inconsistent with reform. This was despite the fact that the inclusion of consumers on health boards was instigated as a policy to empower consumers and give them control over services. Roy & Cain (2001: 422) described people living with HIV/AIDS demanding a say in the delivery of services and organising themselves 'to gain more power and influence in their local community'.

However, the transformation from organisations *run* by people living with HIV/AIDS to people living with HIV/AIDS *sitting on committees or boards* was said to ‘diminish the role and influence’ of the service user (Roy & Cain 2001: 430). Service organisations appeared to have little interest in challenges to the system, despite claims of willingness to hear the service user voice.

The majority of the papers reviewed described some form of formal meeting between service users and professionals as the particular way of carrying out the ‘business of involvement’. Instigating involvement allowed professionals to maintain control of the form and level of participation through meeting formats and determining meeting agendas (Hodge 2005;Rutter *et al.* 2004). For example, in their study of user involvement in mental health service planning and delivery, Rutter *et al.* reported that mental health service users described meetings with professionals as ‘inhibiting self-expression and distorting legitimate patient concerns’ (2004: 1797). The service users further reported that in meetings with professionals they felt marginalised, overwhelmed and were expected to act like professionals (2004: 1981).

Expert knowledge, experiential knowledge

A number of authors suggested that expert knowledge and patient experiential knowledge were differently valued, with professionals using their knowledge and the authority it gave them to retain power over decision-making and control service users (Callaghan & Wistow 2006a;Callaghan & Wistow 2006b;Hodge 2005). Knowledge in the form of traditional scientific rationalism was reported as valued over other forms of knowledge in both service development and research settings. Service users’ experiential and diverse forms of knowledge were not considered a legitimate basis for decision-making (Callaghan & Wistow 2006a;Callaghan & Wistow 2006b;Hodge 2005;Malone *et al.* 2006;Martin 2008). Malone *et al*. (Malone *et al.* 2006) reflected on their experience of gaining Institutional Review Board (IRB)[5] consent to carry out a community based research project on tobacco control. In this study, the community researchers wanted to survey shops undertaking illegal single cigarette sales, acting as 'mystery shoppers' to identify shops selling cigarettes in this illegal form. The community researchers had rejected other methods, such as observation of shop sales, as too time-consuming or dangerous for researchers to be loitering in relatively unsafe neighbourhoods. The IRB, who were mainly used to dealing with traditional biomedical studies, refused the study permission on the grounds that the university could be sued for entrapment of shop owners despite university and community researchers providing legal assurances that the research would not constitute entrapment. The experience led the authors to conclude that research structures serve to protect the already powerful research institutions and existing forms of research. New forms of collecting data based on community experiences of how best to collect data were prevented. This was seen as perpetuating inequalities by preventing research aimed at changing poor environments.

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[5] Institutional Review Boards are the North American equivalent of Research Ethics Committees.

Hodge (2005b) reported how professionals on a mental health forum steered meeting agendas away from discussions of electroconvulsive therapy (ECT), even though this treatment was of grave concern to the forum's service user members. Professionals argued that their role was to commission services based on the view of clinical evidence and current clinical practice and that a debate on ECT with service users would not change this policy (Hodge 2005). Hodge further concluded that the structure of user involvement forums reflected the inherent inequality and power differentials in the wider mental health system. Professionals wanted access to service users' subjective experience of mental health services in order to demonstrate compliance with user involvement policy and to be seen to be listening to service user views. However, whilst service users were expected to share their experiences, professionals were not expected to share their experiences of working in the mental health system in return. Hodge argues that this results in an inequality between service users and professionals that reflects and reinforces the unequal power relations inherent within the mental health system (Hodge 2005b).

Martin (2008) investigated the involvement of patients in an NHS cancer genetics service using interviews, participant observation and documentary analysis. Results from this study contrast with much of the literature reporting the value of lay experience and experiential knowledge in user involvement activities. Despite the lack of electoral or statistical representativeness of the service users involved in the activities Martin investigated, professionals did not use this to undermine their legitimacy. Rather, professionals ascribed a certain degree of representative legitimacy to involved service users on the basis of their status as patients or lay members which provided a necessary contrast to professionals' clinical expertise. For professionals, this enabled service users to contribute to issues of universal relevance to the wider population of patients and the public, such as communication and patient satisfaction. Martin argues that professionals afforded legitimacy to service users, albeit within restricted domains, because they needed to demonstrate to external funders that user involvement was being granted legitimacy and influence, and was not simply being marginalized (Martin 2008).

Attempts to redress the power imbalance

Some authors reported the implementation of mechanisms to address the unequal balance of power between professionals and service users, such as having the position of meeting chair filled by a service user (Hodge 2005;Jones *et al.* 2006) and increasing the number of service users attending meetings (Elliott 1996;Hodge 2005). However, Elliot and Hodge argue that these measures did little to change power relations between professionals and service users. Elliot (1996) describes how in Georgia, USA, the policy requirement that half the membership of community service boards should be filled by service users did not lead to improved mental health services. Instead, the policy placed demands on the advocacy community who were expected to supply large numbers of volunteers to the community boards. Hodge (2005b) describes a mental health forum in the UK which instigated a service user as the chair as a 'conscious and explicit acknowledgement of the need to address unequal power relations in the forum' (Hodge 2005: 166). However she argued that significant power remained with professionals in the forum and the two workers employed to carry out actions agreed by the forum.

In summary then, few authors provided a critical evaluation of, or commentary on, participation. Whilst the general consensus from the papers reviewed was that professionally-led and professionally-controlled forms of participation did little to challenge or transform the relationship between professionals and service users, most authors linked this to a failure of poor practice rather than questioning the policy assumptions at the heart of user involvement policy. The ‘power’ being referred to was a power which enabled professionals to retain control over health services or research practices as they were despite offering appearances of wanting to listen to the voice of the service user. So, in the case of Hodge’s (2005b) exploration of service user involvement in mental health services, service user calls to put an end to treatments such as ECT were played down. Valuing professionals’ expert knowledge over service user’s experiential knowledge further enabled professionals to retain control over decision-making through questioning the representativeness of service users and consequently undermining the value of their knowledge. Even in cases such as Martin’s (2008) where the experiential knowledge of service users was actively encouraged and legitimised, the service domains to which service users could contribute were limited. I now go on to explore how the literature portrayed a more nuanced view of power within professional and patient groupings than that portrayed in the policy literature.

Hierarchies of power within professional groupings

Whilst the policy literature on user involvement tends to portray professionals as homogeneously powerful, the literature reviewed suggests that the reality is more nuanced and that power may be expressed differently within patient and professional groupings.

A common theme arising from the literature suggests that it may be easier for certain groups of professionals to cede power to service users (Anderson *et al.* 2006;Clarke & Mass 1998;Hodge 2005;Rutter *et al*. 2004). Anderson *et al.'s* (2006) study of user involvement in two English Primary Care Trusts (PCTs) found that managers responsible for establishing user involvement were willing to change the way they operated so that they were accessible and flexible and were prepared to remodel decision-making processes to incorporate service user input. However, later on when plans for a healthy living centre were to be implemented, managers were no longer involved and relations between service users and other groups of professionals broke down. Receptionists felt they had not been included in the decision-making process and were less willing to cede power to implement decisions made by local people. Anderson comments that the receptionists did not share the same vision of involvement with local people as full partners as the managers did (Anderson *et al.* 2006). This is perhaps because in comparison to managers they had less power to give away.

In Rutter *et al.*'s study (2004) of user involvement in mental health services, of all professional and service user groupings, nurses are described as feeling the least empowered. They felt criticised by service users whilst at the same time being expected, by other health care professionals, to empower service users. In contrast, Clarke and Mass (1998) found that the organisational structure of the Primary Health Care Nursing Centre, where nurses worked independently of other professionals, allowed nurses to work in new collaborative ways with patients. However, doctors were reluctant to work with the centre or refer patients to the centre, which negatively influenced the nurses’ ability to demonstrate key attributes of collaboration: respect, team working and non-hierarchical relationships (Clarke & Mass 1998).

The health system itself, within which professionals and service users were attempting to garner change, has been described as restricting change and maintaining the status quo even when professionals agreed with radical suggestions put forward by service users. In Hodge’s evaluation of user involvement in mental health service development, a service user suggested spiritualism as one of the forms of treatment on offer for mental health illnesses. Despite agreeing that spiritualism could be offered as a treatment option, the professionals working with service users felt powerless to introduce this idea into the system because this was not regarded as an appropriate treatment for mental health illness (Hodge 2005). However, Callaghan and Wistow (2006a) observed that professionals aligned with a social model of health and illness used public involvement as a means to challenge the dominance of professionals who shaped services based on the medical model of health and illness.

Hierarchies of power within service user groupings

Hierarchies of power have been found to exist within the category of ‘service user’. This suggests that the portrayal of patients as ‘disempowered’ and professionals as ‘empowered’, as implied in policy documents, is too simplistic. Some service users were excluded from involvement activities by other service users as they were seen as a threat or were not considered ‘legitimate’ because of the way they managed or interpreted their illness or condition (Buck *et al.* 2004;Eyre & Gauld 2003). Buck *et al.* (2004) evaluated a project to involve homeless people in developing health services for the homeless. The participants (homeless and ex-homeless people) involved in the consumer advisory board differentiated themselves from another group of homeless people which they categorised as ‘chronically homeless’ (Buck *et al.* 2004: 519). The participating group suggested that the chronically homeless group would not be suitable as members of the board as they wished to remain homeless and would therefore develop services that would maintain their homeless state, such as soup kitchens. Hodge (2005b), using observations and interviews, evaluated the involvement of mental health service users in developing services and found that users had different reasons for taking part in developing services: some saw themselves as part of the user/survivor movement; others saw it as an opportunity to distance themselves from the identity of ‘service user’, aligning themselves with the officials who attended the forum.

2.3. Concepts of empowerment

Just under half of the publications in the review (n=46) discussed empowerment in relation to forms of participation of service users in health service development and research. In this section, I first discuss how authors of the reviewed publications defined empowerment. Following that, I discuss the role of empowerment in user involvement and other forms of patient participation according to six themes generated through the literature synthesis. Finally, I discuss whether the reviewed literature provides any consensus on the empowering effect of involving service users in service development or research as the user involvement policy literature suggests.

Defining empowerment

Few authors explicitly defined empowerment despite referring to the term in the context of user involvement and other forms of patient participation (for example, see Mayo & Tsey 2009; Reed *et al.* 2004;Restall & Strutt 2008;Yates *et al.* 1997). Mayo and Tsey (2009) frequently mentioned the term 'empowerment' throughout their paper evaluating university and community research collaborations, but never defined the term. As part of the evaluation of the research collaboration, Mayo and Tsey conducted interviews with community and professional researchers involved in the collaborative research. Extracts from the interviews suggest that empowerment was a term frequently employed by participants. In one interview extract, the reader is told that community attitudes toward university researchers 'shifts as staff understanding of empowerment grows and people develop hope in the system, and commit to it.'

(Mayo & Tsey 2009: 137). Yet Mayo and Tsey never share with the reader what exactly staff understanding of empowerment was or where the rationale for empowerment within a research project originated from.

McLean (1995), Kerr *et al.* (2006), and Segal *et al.* (1995), all conducting research within the mental health field, discussed empowerment as ideologically aligned with grass roots survivor movements. McLean (1995) and Segal *et al.* (1995) further acknowledged that despite common usage of the term, it is rarely defined. Clarke & Mass (1998) stated that empowerment is conceptually and operationally difficult to define.

The role of empowerment in user involvement

The literature reviewed provides little consensus on the role of empowerment in user involvement, or the relationship between user involvement and empowerment. I used the synthesis to develop six categories of empowerment evident in the literature, with some papers drawing on more than one category (see Table 2.4, overleaf).

Table 2.4 Categories of empowerment

Empowerment category	Publications	Summary
Pre-requisite of participation	Anderson *et al.* 2006;Barnes & Walker 1996;Braun *et al.* 2006;Jacklin & Kinoshameg 2008;Manning *et al.* 2000;Ochocka *et al.* 2002;Segal *et al.* 1995	Empowerment defined as: process for local people, excluded and marginalised groups to gain 'confidence', 'control' and the 'necessary skills' to enable them to influence the organisational and societal structures within which they live.
Outcome of participation	Barnes & Prior 1995;Buck *et al.* 2004;Doyle & Timonen 2010;Elliott 1996;Linhorst & Eckert 2002;Powers & Tiffany 2006;Reed *et al.* 2004;Roy & Cain 2001;Salmon *et al.* 2010;Thomas *et al.* 2001	Participating in either research or service development was personally empowering for those involved, often cited as *the* outcome of the involvement initiative (over research or service development outcomes). Doyle and Timonen (2010) acknowledged that the empowering effect of involvement was difficult to quantify.
Means to *and* an end of participation	Clarke & Mass 1998;Mayo & Tsey 2009	Empowerment as a personal 'process' to reach goals, as well as an 'outcome' of participation through involvement in autonomous decision-making.
Transforming patients from passive to active participants	Carney *et al.* 2006;Freedman 2006;Wistow & Barnes 1993	User involvement as part of a wider initiative to empower patients to become active in their own healthcare.

Empowerment category	Publications	Summary
Transforming patient voice	Barnes & Walker 1996;Gawith & Abrams 2006;Hodge 2005;Kerr *et al.* 2006;Linhorst *et al.* 2001;Manning *et al.* 2000;O'Donnell *et al.* 1998;Rutter *et al.* 2004;Teram *et al.* 2005;Wistow & Barnes 1993	Service users participating in user involvement activities felt they had been empowered through having been 'given a voice' to express their concerns. However, enabling voices to be heard does not necessarily imply that those in authority have to listen to and act on these views.
Empowerment as psychological support and recovery	Gawith & Abrams 2006;Kerr *et al.* 2006;McLean 1995;O'Donnell *et al.* 1998;Trainor *et al.* 1997	All the papers in this category were concerned with mental health problems. Participation in user involvement activities allows those participating to view themselves in a positive light in contrast to the stigma imposed on them by society due to their mental health problems.

Empowerment as a pre-requisite or outcome of participation

Some authors suggested that empowerment is a prerequisite of participation - users need to be empowered, through developing their confidence, in order to participate, otherwise they cannot challenge those who are seen to be more powerful and to have knowledge which is deemed of greater value than lay knowledge (Anderson *et al.* 2006;Barnes & Walker 1996;Clarke & Mass 1998;Manning *et al*. 2000;Segal *et al*. 1995)

Others presented user involvement, or the participation of service users, as an empowerment intervention, suggesting that the very act of participating in making decisions about health services or research is empowering for those involved (Abelson *et al.* 2004;Barnes & Walker 1996;Buck *et al*. 2004;Doyle & Timonen 2010;Freedman 2006;Linhorst & Eckert 2002;Thomas *et al*. 2001). Barnes & Walker (1996) carried out an evaluation of older people's involvement in 'user panels' to influence service planning and provision in Scotland. They found that through the 'user panels', older people were encouraged to challenge professionals. This experience extended beyond the 'user panels' to other aspects of their lives. Participants were able to challenge professionals they had contact with outside of the user panels and increase their participation in other areas such as joining committees or voting in elections. Salmon *et al.* (2010) noted an empowering effect for illicit drug users taking part in a research project. In the course of doing research the women drug users could see their personal experiences as part of systems and patterns relating to failings in society rather than individual failings. However, Salmon *et al.* caution that research as a tool for activism and empowerment has its limits – it could not, for example, improve the material conditions of the women undertaking the research.

The papers reviewed, therefore, focus on empowerment as an individual and psychological process rather than empowerment in terms of increasing access to resources. This is in contrast to some observations in the anthropological literature. For example, Cheater (1999) notes how the meaning of the term 'empowerment' has changed from the 1970s when it was used to describe access to resources to its current meaning as a right to express an opinion or have a voice. James' (1999) analysis of participation in the development field, leads her to criticise the term 'empowerment' as concerned only with sharing management responsibility and decision-making, without entailing any direct control of resources or scope to join others at the same level in the structure.

Transforming patients

Whilst three papers defined empowerment as the transformation of patients from passive to active participants, the authors of ten papers were more specific in this description and discussed user involvement and empowerment as a *means to give service users a voice* (see Table 2.4). However, as Hodge (2005b), Kerr *et al.* (2006) and Linhorst *et al.* (2001) suggest, empowerment as enabling voices to be heard does not necessarily imply that those in authority have to listen and act on these views. Authors of both papers asserted that the goal of user involvement for professionals was to allow patients to 'have their voices heard' (Hodge 2005;Kerr *et al.* 2006;Linhorst *et al.* 2001). In a number of cases where user involvement was described by professionals as giving service users a voice, evaluation demonstrated that either little was done in response to service users' expressed wishes or service users were restricted in what they could make decisions on (Hodge 2005;Linhorst *et al*. 2001). Linhorst *et al.*'s (2001) qualitative evaluation of service user involvement on the board of a psychiatric hospital found that service users felt they had no power or input into organisational decision-making. Changes that service users' did manage to implement were at a domestic level which improved day-to-day living for in-patients, such as extending visiting hours, or changing the types of drinks available in the canteen. Influencing far-reaching organisational change, such as policies on treatment planning and provision of therapeutic activities, was harder to achieve.

Does user involvement lead to empowerment of service users?

Some authors made the distinction between 'user involvement' (defined as service-led initiatives to involve the community) and 'community participation' (defined as local residents empowered to define and establish local health care), stating that it is the latter which is empowering (Halseth & Williams 1999;Manning *et al*. 2000;O'Neill 1992). A number of evaluations of user involvement demonstrated that formal structures of involvement were actually disempowering for service users (Bowl 1996;Halseth & Williams 1999;Manning *et al.* 2000;O'Donnell *et al*. 1998;Roy & Cain 2001). Drawing on observations of user involvement activities in local authority mental health services and interviews with service users and professionals participating in service development, Bowl (1996) describes the experience of service users. He reported that service users found the process of sitting on planning committees disempowering: they were unclear what weight their views carried, unclear of the scope of the committee and the purpose of their participation, and were unsettled by the jargon used by professionals. Professionals' negative opinions and perceptions of user involvement (that users are not capable of participation or that staff can best gauge patient needs) disempowered users further by denying them a chance to participate. Bowl (1996) and Callaghan and Wistow (2006b) argued that service users were further disempowered by professionals who questioned service users' ability to adequately represent the service user population. This attitude was used to justify limited involvement of service users in shaping services. Professionals thought that carer interests may dominate the meetings and service users were not clear to what extent they were being asked to represent their own views or those of a wider group (Callaghan & Wistow 2006b).

The policy assumption that service users, by the virtue of having experienced ill health and health services, can empower other service users was not always evident in the literature reviewed. McLean's (1995) ethnographic study of a consumer-run mental health drop-in centre found that two successive centre managers, despite being previous users of mental health services, treated those using the centre as subordinates to themselves. Both managers had been dismissed from prior employment due to their mental health. McLean argued that they used the position as centre manager to recover and re-empower themselves, at the expense of disempowering users of the centre. One centre manager assigned mundane tasks, such as sweeping floor, to centre users, whilst retaining for him the more intellectually challenging tasks, such as advocacy and managing the centre. McLean argued that since the centre managers lacked an understanding of the consumer movement, its political roots and empowering mission, they reinforced the traditional structures of mental health services where service users are dominated by service providers (McLean 1995). This suggests that shared experience of an illness may not in itself be empowering, a point I shall return to in Chapter 8.

Only one author addressed the question of why people decide to participate and whether this is concerned with empowering themselves or not. In her interviews with service users of a consumer-run mental health drop in centre, McLean (1995) found that despite the dissatisfaction they had with the mental health system, most service users did not use the centre for ‘consumer empowerment’ (1995: 1061), but rather to pass the time or socialise, judged by the author not to constitute an empowering activity. McLean found surprising results when she specifically asked service users about empowerment. Only four of 17 respondents felt that empowerment (defined by the author for interviewees as ‘gaining more control over yourself and your treatment’) had been encouraged at the centre despite the centre being run by a consumer organisation with an empowerment ethos (McLean 1995).

The way power and empowerment is operationalised in user involvement situations may reflect specific assumptions about the purpose and ethos of participation. The evaluation conducted by Callaghan and Wistow (2006b) compared two examples of user involvement in service development: one where user involvement was seen as a way to improve services; and the other which emphasised improving social and environmental determinants of health through the public’s contribution and voice in decision-making. The first approach to involving service users was to maintain roles consistent with traditional patient and professional relationships, whereas the second approach used existing patient networks as vehicles for user involvement.

2.4. Discussion and conclusion

This review has shown that power and empowerment are complex, multifaceted concepts, frequently referred to by authors discussing user involvement and other forms of patient participation in health. Yet the concepts are often ill-defined and theoretically ungrounded. The papers discussed in this review highlight that there is little consensus on the role of empowerment in user involvement, or the relationship between user involvement and empowerment. Empowerment was discussed in a number of ways: as a pre-requisite for involvement as well as an outcome of involvement, with some authors alluding to both definitions in their analysis. Other interpretations of empowerment related to the transformation of patient roles from passive to active and empowerment through involvement as psychological support and recovery from illness. However, a number of authors concluded that user involvement did not necessarily empower service users, with some authors reporting that the formal structures of involvement were actually disempowering for service users. The reviewed literature failed to answer my questions about where the desire to empower patients originated from and whether professionals charged with implementing user involvement policies shared the desire, inherent in the policy, to empower patients.

Similarly, there was no evidence that a transfer of power from professionals to service users, through the mechanism of user involvement, occurred. As was the case with the concept of empowerment, few papers raised the question whether the policy imperative to transfer power was desired by those charged with implementing user involvement policy – patients and NHS professionals.

The general consensus from the papers reviewed was that formal, professionally initiated forms of involvement upheld traditional patient-professional relationships, such as patients being subordinate to clinicians. The literature reviewed pointed to a more nuanced definition of power than that discussed in the policy literature. There was evidence that hierarchies of power existed within professional and service user groups, which had an influence on outcomes of involvement.

With the exception of McLean (1995), none of the papers reviewed addressed whether certain groups of patients through their involvement or participation in health service development or research were empowered at the expense of others. Nor is this discussed in the policy literature. A number of authors did however give examples of service users specifically excluding other groups of service users or that certain groups of service users were harder to identify and involve (Buck *et al.* 2004;Eyre & Gauld 2003). Assuming that involvement in service development and research engenders empowerment, as the policy literature suggests, certain patient groups may have the opportunity to become empowered whilst others will not. A further question the review raises is whether the benefits of user involvement in terms of patient empowerment are limited to those who decide to participate in involvement initiatives or whether these benefits extend to those who choose not to participate.

The vast majority of papers reviewed lacked a theoretical basis or grounding in their discussion of power and empowerment. Power was conceived as ‘bad’ if professionals held power over service users. Empowerment was conceived as a personality quality, rendering the patient assertive and outspoken, and attributing them with a sense of individual control and power. As Ponic and colleagues (Ponic *et al*. 2010: 333) point out, the lack of theoretical perspectives informing participation can lead to an assumption that participation in health research is necessarily a ‘good’ thing.

In the next chapter, therefore, I explore two theoretical frameworks within which to ground discussions of user involvement and the empirical data central to this thesis. The first, Lukes’ radical view of power, proposes novel way of how to conceptualise power theoretically and how to study power structures and relations empirically (Lukes 2005). The second framework concerns the concepts of biosociality and biological citizenship. These concepts, whilst less explicitly focused on power and empowerment, propose ways of investigating the link between the emergence of new patient groups and identities and changing practices of science and medicine.

Chapter 3: Theoretical frameworks

When I embarked on this thesis, the topic of user involvement was relatively new to me and, as I have said in Chapter 1, I was struck by the prominence of the concepts of power and empowerment within the user involvement policy and academic literature. In particular, I was interested in the suggestions made by proponents of user involvement that implementation of the policy will lead to a transfer power from professionals to patients, giving patients a 'voice' in decision-making about publicly funded health services and research. I therefore felt that a theory based on understanding power would be necessary, particularly as most academic explorations of user involvement lack a theoretical basis or grounding within which to locate discussions on power and empowerment, as I demonstrated through a review of the literature in the previous chapter (see Chapter 2). I was thus drawn to Stephen Lukes' *three dimensional view of power* which sought to answer questions on what constitutes power in the context of policy and political arena and who has control over decision-making and the political agenda.

Empirically, however, data collection led me to think that a theoretical approach solely concerned with power may not answer the whole story. As I witnessed, and contributed to, the development of stroke 'user groups' questions were raised: How do those charged with implementing user involvement policy organise themselves? How does policy implementation create new subjectivities and practices? How do the patient groupings that emerge from professionally led implementation of user involvement contrast with patient groupings or collectives emerging through grass roots activism and embodied health movements?

I felt that two related concepts - *biosociality* and *biological citizenship* – may help to frame some of the observations I was making, as stroke survivors were identifying around a shared biological identity of stroke. Social and political scientists are increasingly asking questions about biological citizenship and its implications for how we understand the relationship between the state and civil society (Orsini 2008), and how the practices of medicine, health service delivery and public health research shape the formation of new subjects and citizen and patient groupings (Klawiter 2008, Good 1994). Good argues that ‘if we are to understand how medicine constructs its objects, we will need to join together critical studies of practices and the analysis of embodied experience’ (Good 1994:69).

In the following sections, I describe the two frameworks I shall be grounding my empirical data within. First, I outline Lukes’ theory of three dimensional power, how the theory has been applied and limitations of the theory. Second, I introduce the concepts of biosociality and biological citizenship and discuss the ways these concepts have been applied within the healthcare literature and their limitations.

3.1. Lukes' three-dimensional view of power

Steven Lukes has been recognised as one of the more influential power theorists (Beland 2006;Clegg 1989). Lukes, a British political and social theorist currently working in the United States of America (USA), published his influential text *Power: a radical view* in 1974. The text was republished in 2005 with a new introduction to situate the original work and two new chapters critiquing and reconsidering the original theory within broader discussions on the concept of power (Lukes 2005). Lukes suggests that power may be understood as having three dimensions or 'faces' - alternative ways of understanding power. Lukes' theory builds on two prior dimensions. The first dimension is based on the traditional view of power put forward by pluralists in the 1950s. The second dimension is that of 'the two faces of power' proposed by Barach and Baratz (1962). The third dimension is that which Lukes developed.

Lukes' theory concentrates on decision-making in a political arena and the control over the political agenda. He developed his theory as a contribution to the debate amongst political scientists and sociologists at the time on how to conceptualise power theoretically and how to study power structures and relations empirically (Lukes 2005). This question was particularly pertinent given that Lukes took a view of power as being able to produce its effects in a 'remarkable variety of ways, some of them indirect, some of them hidden, and that, indeed, it is at its most effective when least accessible to observation'(Lukes & Haglund 2005: 55). If power is viewed as something at its most effective when hidden, then this leads to the question of how to empirically study power (Lukes & Haglund 2005). Lukes' three-dimensional view of power (built upon insights from Gramsci, whose theory of 'hegemony' and how consent to capitalist exploitation was secured under contemporary conditions, in particular democratic ones) was of relevance and interest to those understanding the persistence of capitalism, compliance, democracy, rebellion and protest in the early 1970s (Lukes 2005).

The one-dimensional view of power: observable decision-making

The first dimension of power was based on a theory of power developed by American political scientist Robert Dahl. Dahl's empirical work was based on American local government politics, specifically in New Haven, Connecticut, where he examined power structures within the city. Dahl was a pluralist and critic of Marxist inspired ideas of a 'ruling elite' (Lukes 2005). Pluralists, such as Dahl, took the view that decision-making and politics occur within a framework of government but that different interest groups can use resources to exert influence. Since different actors and interest groups exist in different 'issue-areas', there is no overall ruling elite and power is openly and diversely distributed (Lukes 2005: 5). Pluralists therefore conceived power, not as a physical entity that individuals either have or do not have, but as flowing from a variety of different sources. People are powerful because they control various resources, and these resources can be used to force others to do what one wants. Power, according to pluralists, meant participation in decision-making in a series of observable, concrete decisions; for example, the power of a person, A, to make another person, B, act in a particular way. Critical to this definition of power was the measurement of power through responses to it. Responses were taken as an indication of the power which stood as the cause of the measured reaction; for example, the power of A could be measured through the response of B (Gaventa 1980;Clegg 1989). However, Bachrach and Baratz (1962) argued that a pluralist position concentrates on the *exercise* of observable power, with the result that the second dimension of power – *non-decision making* – is overlooked.

The two-dimensional view of power: non-decision making

Bachrach and Baratz developed the notion that power has a second 'face', arguing that the weakness of the pluralists' view of power was the focus on concrete acts of decision-making by interest groups. By observing only the things which happen, one neglects to consider that the effects of power may manifest themselves not only in doing things but ensuring that things do not get done (Bachrach & Baratz 1963). Power therefore, is exercised not just on participants within the decision-making arenas but also to ensure that certain participants and issues are excluded from the decision-making arena in the first place (Gaventa 1982). Gaventa argues that applying this view of power to the political behaviour of deprived groups provides explanations for 'quiescence in the face of glaring inequalities' which would have been obscured if only the one-dimensional view had been applied (Gaventa 1982: 9). Using the example of A and B again, Dahl's theory cannot explain the situation whereby B responds to A, despite A having done nothing in the way of a concrete action aimed at B prior to B's response. For instance, Crenson (1971) tested, empirically, the two-dimensional view of power to explain why certain cities in the USA were slow to raise the issue of air pollution caused by industry and late to develop controls on industry-related air pollution. Crenson argues that the differences in responses to air pollution cannot be explained by differences in levels of air pollution or characteristics of the local population but rather by the influence of industry on local politics and the economy. An industry with a ‘reputation for power’ was enough to prevent the issue of air pollution from being raised for fear of the ensuing job losses (Crenson 1971). Bachrach and Baratz labelled this approach to exercising power by confining the scope of decision-making to relatively ‘safe’ issues or preventing issues from being raised in the first place, ‘non-decision making’ (1963).

The three-dimensional view of power: the ability to act against the interests of the powerless

While Lukes did not doubt that the two-dimensional view of power was an advance on the one-dimensional view, as it incorporates into the analysis of power the question of control over agendas and how issues are kept out of the political process, he believed the theory to be inadequate on three accounts. First, it was still too committed to the analysis of overt behaviour of concrete decisions arising out of situations of conflict. Second, the two-dimensional view assumes that power is only exercised in situations of conflict. Third, non-decision making was assumed to only occur when there are grievances; if people have no grievances, then they have no interests that are harmed by the use of power (Lukes 2005). However, Lukes argued that the

> most insidious exercise of power [is] to prevent people, to whatever degree, from having grievances by shaping their perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things, either because they can see or imagine no alternative to it, or because they see it as natural and unchangeable, or because they value it as divinely ordained or beneficial (Lukes 2005: 28).

Therefore, Lukes' three-dimensional view of power builds on the first two dimensions as it takes into account the invisible face of power (see Table 3.1, overleaf). Again, returning to A and B, Lukes argues that 'A exercises power over B when A affects B in a manner contrary to B's interests' (2005: 37). Power, therefore, shapes the world so that people accept things as they are, as they have been led to believe there is no alternative or that they cannot change things (Lukes 2005). Applying a three-dimensional view of power asks the question why things do not occur. For example, why, in a situation of 'domination of a non-élite by an élite, does challenge to that domination not occur?' (Gaventa 1982: 3). As I will argue in subsequent chapters, Lukes' theory helps explain some of my observations such as why health care professionals appear to have accepted the policy of user involvement without overt dissent, despite the paucity of evidence for some of the claims of the policy and why stroke patient activism has failed to develop.

Table 3.1 How the three views compare

	Features and definition	Strengths/weaknesses
One-dimensional view	Focus on concrete, observable behaviour in the making of decisions on issues over which there is an observable conflict of interest.	• Grievances are assumed to be recognised and acted upon. • Participation in decision-making assumed to take place within decision-making arenas and, furthermore, this is assumed to be open to everyone.
Two-dimensional view	Power may be exercised by confining the scope of decision-making to relatively safe issues or to prevent issues being matters of open discussion. Incorporates the notions of 'non-decision making' and 'mobilisation of bias', whereby some issues are organised into politics while others are organised out of politics.	• Advances the one-dimensional view as the analysis incorporates the question of control over the agenda and the way in which potential issues are kept out of the decision-making process. • Grievances remain observable.
Three-dimensional view	Power is exercised by preventing people from having grievances in the first place. This occurs through the shaping of perceptions, cognitions and preferences in such a way that they accept their role in the existing order of things.	• Advances the two-dimensional view by asking the questions: How does power affect conceptions of grievances? Why do things *not* occur? • Focuses on non-observable power.

Lukes' three-dimensional view of power has been applied to analyses of empirical data in a range of settings. Gaventa's *Power and powerlessness: Quiescence and rebellion in an Appalachian Valley* (1982) is a study of the conflicts arising between the financial interests of the coal and land companies and the rights of the indigenous population. Appalachia is rich in natural resources, but the local population remain amongst the poorest in the United States. Gaventa sought to understand why the indigenous Appalachian miners did not rebel in the face of glaring inequalities, demonstrating that the exercise of power has as much to do with preventing decisions as well as bringing them about. Taking a historical perspective, in the one-dimensional view of power, conflicts over resources were observed between the local non-élites (the miners) and outsiders with economic interest in the area (primarily British mining companies), with the latter tending to prevail. In the two-dimensional view, the native, and powerless, Appalachian miners remained outside of the decision-making arena, expression of their discontent limited through a range of factors including anticipation of defeat, threat of sanctions such as withdrawal of pensions, home and jobs, and the application of symbolic labels such as 'outsider' and 'troublemaker' subtly discrediting those raising grievances (Gaventa 1982: 254). In the three-dimensional view, continual defeat and participation denied over time lead the miners to a sense of powerlessness, acceptance of the role of non-participation, and failure to develop the skills, organisation and consciousness of political action. When the routine of non-action was broken, in the case of reformers standing against corrupt union officials to improve the miners' situation, myths, rumours and symbols were deployed to channel support away from the challenge. The reformers were labelled 'outsiders' and accused of not working hard enough for the miners' cause in their union roles. Powerlessness and political inertia on the part of the miners resulted in the miners perceiving reformers as part of the as part of the same elite as the established regime. Both the reformers and the established elite were seen as having access to power, position and money. In not being able to distinguish between the two regimes, it was safer for the miners to support the established regime in light of the possible costs (loss of jobs, pensions, homes) that not supporting the incumbents could incur (Gaventa 1982).

Culley and Hughey (2008) undertook a three-year participant observation study of public participation in a hazardous waste dispute. Participation was limited and citizen influence manipulated via control of resources, agenda setting, shaping conceptions about legitimate forms of participation, and use of important symbols and imagery. The power enacted by industry was to ensure that, through imagery of industry as a 'good neighbour' and economic benefactor; those who opposed the industry-led clean-up investigations were labelled as anti-community or anti-economy (Culley & Hughey 2008).

Other studies in a range of settings have further argued how the three-dimensional view of power helps to understand: how social policy creates socio-economic dependency and reduced levels of political activity (Carney 2010; Ward & Mullender 1991); how behaviour is regulated to maintain stability within an organisation (Napier-Moore 2007); and how through a supportive public the medical profession in that UK have been able to resist successive governments' increased manegarialism of the NHS (Hunter 1994).

Despite power being at the root of empowerment, power is rarely discussed in the context of empowerment (Culley & Hughey 2008). Although Gaventa (1982) does not explicitly use the term 'empowerment' in his book, he argues that the three dimensions of power are useful, not only for explaining how quiescence is maintained, but to identify which aspects of powerlessness must be overcome for successful protest (Gaventa 1982). Two sets of authors draw on the notion of power as having three dimensions to examine empowerment strategies for mental health service users (Masterson & Owen 2006) and in school-based sex and relationships education (Spencer *et al.* 2008).

In a review of the literature reporting empowerment strategies for mental health service users, Masterson and Owen (2006) argue that consumerism has affected a degree of empowerment through the formal transfer of power. However, by applying Lukes' theory of power they illustrates how limited this apparent transfer of power is. In the one-dimensional view, power can be said to have been transferred in that mental health service users may now be encouraged to take some decisions about the care and services they receive. The two and three-dimensional views however, show that power may still be exercised at the expense of service users. Professionals may give the appearance of facilitating service user decision-making, yet they subtly exert control over service user decisions, as they continue to 'set the terms of what can and cannot be debated' and prevent 'significant change from occurring' (Masterson & Owen 2006: 25).

The authors further argue that power may be exercised by the manipulation of roles and identities, so that social groups may be persuaded to accept certain situations without conflict. It may be argued that the medical concept of mental illness exemplifies the exercise of power at Lukes' three-dimensional view. Power relations between mental health patients and professionals are maintained by a society persuaded to accept certain situations without challenge. In Western society, the social constructionists' argument that mental illness is comprised of 'subjective labels of social deviance that facilitate social control, rather than formally valid medical conditions' is not widely considered, and thus power relations are maintained (Masterson & Owen 2006: 21).

Spencer *et al*. (2008) draw on Lukes' three-dimensional analysis of power in their analysis of the concept of empowerment in school-based sex and relationships education (SRE) in England. They argue that Lukes' third dimension of power illustrates how dominant discourses and frameworks of knowledge come to shape and define the parameters of 'normal' and 'appropriate' sexual behaviour and experiences for young people. SRE policy and practice focuses on preparing young people to become sexually risk-averse, responsible 'adult' individuals.

Incorporating empowerment into the analysis, Spencer *et al*. (2008) argue that an empowerment approach to SRE would therefore require young people themselves to resist and redefine the dominant discourses about young people and youth sexuality. However, their research questions the extent to which the school environment can engage with, accept and facilitate young people's resistance to dominant discourses about youth sexuality. Despite SRE in schools utilising the language of empowerment, the practice of SRE is determined by government-led priorities aimed at reducing the 'risks' to young people's sexual health. Any resistance young people may make to the dominant discourse would be interpreted as confirmation of the notion that young people lack the knowledge and maturity to set their own agendas. The authors conclude that SRE serves to regulate, rather than empower, young people’s sexual attitudes and behaviours (Spencer *et al.* 2008).

Initiatives to empower service users could, referring to Lukes’ radical view of power, be seen as attempts to shape subjects according to professionally accepted and defined discourses, for example, by encouraging certain qualities such as self-management, responsibility for own health, competency and knowledge of one’s own health, as I shall show in subsequent chapters. The three-dimensional view of power, therefore, draws attention to how people’s desires and interests are shaped by the dominant knowledge systems.

Having outlined the three-dimensional view of power and how it has been applied to empirical data in a range of settings, I now discuss my reasons for applying Lukes’ theory to the empirical data collected in this study.

Application of the three-dimensional view of power to user involvement.

While the work of Steven Lukes has been applied in a number of empirical cases, some specifically focusing on community participation (Carney 2010;Culley & Hughey 2008;Gaventa 1982), it has not been directly applied empirically to the context of user involvement in health service development and health research. Lukes’ theory concentrates on decision-making in a political arena and control over the political agenda. It is appropriate to apply Lukes to the context of user involvement given the inextricable links in the UK between the health service and the political system. The stroke survivors I met through the course of fieldwork were concerned about the health of the NHS, what may become of it, and who would have a say in and control over decisions about the NHS. Furthermore, one of the concerns of academics who have investigated the phenomenon of user involvement is who (patients, health care professionals, researchers, politicians, research funders) has control over the agenda in terms of the health service or research priorities to be discussed. In the case of user involvement in health care settings, an approach which may reveal how the various interests of the different groups are put forward and acted upon, or not, is of importance for understanding the processes and impact of user involvement.

I could immediately see the applicability of power as having multiple dimensions when I read about a series of public consultations organised by the Labour government in 2005 in preparation for a white paper on community health services. At the two-dimensional view, power retention through mobilisation of bias and non-decision making can be observed. The public consultations were criticised by patient groups and participants for restricting debate on community health services through the use of loaded questions endorsing the choice agenda and the increased use of the private sector within the NHS (Gould 2005;Lloyd 2005).

I was particularly drawn towards Lukes' theory in light of acquiescence and inaction that his theory raises (Lukes 2005). As discussed in Chapter 1, stroke service user involvement and stroke activism is somewhat underdeveloped compared to other health areas such as HIV/AIDS, cancer and mental health. Throughout my fieldwork and research, I often found myself asking why stroke activism had not developed, despite stroke survivors having a number of legitimate grievances.

Application of Lukes' theory is further appropriate to my thesis given that one of the questions he posed, and some of the criticism levelled at him, was how to examine and observe those operations of power which are assumed not to be amenable to observation, such as inactivity on the part of researchers to fully investigate research questions generated by stroke survivors despite encouraging 'user defined research', as I shall discuss in Chapter 7. Whilst models or theories may be conceptually useful, the challenge is whether they can be applied to an empirical situation and whether this process allows further understanding of the relationships presented in the model (Gaventa 1982). Given that the central tenet of the two- and three-dimensions of power focuses on non-observable conflict, non-decisions and non-occurrences, it is logical to question how, empirically, can these non-events be observed. It has been argued that the only way to understand what is happening, or not happening, is to immerse oneself in the setting over time (Culley & Hughey 2008;Gaventa 1982). The ethnographic approach of this thesis, incorporating a lengthy period of immersion through participant observation, may enable the unobservable to be observed.

Related to this is a further criticism, at three levels, based on Lukes' main contention that relations of power can be and often are expressed by keeping the powerless unaware of their 'real interests' (Ron 2008: 272). First, Ron argues that the problem of 'real interests' may be better explained through other devices. For example, exercise of power in the third dimension may not be attributable to the powerless not knowing their real interests, but rather, a failure of collective action in the face of existing institutional and structural barriers. Second, Shapiro (2006), critiquing Gaventa's work on the Appalachian mining community, questions how widespread the manipulation of people’s preferences really is. He argues that given the lack of empirical studies on such questions it is unclear how typical the quiescent miners in Gaventa’s study are. Third, it has been argued that the focus on ‘real interests’, and how the researcher ascertains what these are, pushes the researchers into the ‘patronising and illiberal’ position of claiming to have superior knowledge of ‘what the real interests of a given community are’ (Ron 2008: 273).

Despite these limitations, applying Lukes’ theoretical framework to answer questions about the implementation of user involvement policy provides a novel aspect to this thesis. The theory, with its focus on invisible power and why things do not occur, draws particular resonance with questions I found myself asking about why stroke activism and user involvement in the field of stroke had developed less extensively in comparison to other health fields.

However, analysis of the data revealed that through implementation of user involvement policy, new subjectivities and practices were being produced: stroke survivors themselves were creating user involvement social practices of their own making, for their own needs and ends. It seemed, therefore, that an additional theoretical perspective, allowing for embodied action as opposed to political action, would be necessary to aid the exploration of stroke survivor involvement in service development and research. To this end, I looked to Rabinow’s theory of *biosociality* (Rabinow & Rose 2006;Rabinow 2008) and the related concept of *biological citizenship*

(Petryna 2002; Rose 2007) to explore the notion of how user involvement policy implementation may engender the creation of new subjectivities and personhoods.

3.2. Biologically determined citizenship and identity

Brekke (2011) notes how fears in the 1980s and 1990s that genetic exploration and discoveries would result in the isolation of the individual from wider social and political issues have not materialised. On the contrary, several studies have revealed that rather than individualisation or segregation, genetic research has led to the unfolding of new types of socialities forming around different biomedical traits and illnesses, creating new identities and citizenships (Callon & Rabeharisoa 2008;Rabinow 2008;Rose 1996;Rose & Novas 2005;Rapp & Ginsburg 2001). Rabinow and Rose note that we have witnessed a rise in patient groups and individuals who ‘define their citizenship in terms of their rights and obligations to life, health and cure’ (2006: 203). These collectives based around a shared biological identity appear at the juncture between science, the economy and civil society. They are not subordinate in the face of scientific and medical authority, rather they are characterised as partners with biotechnological and research institutions and they are active in research: promoting research, influencing research agendas and putting themselves forward as research subjects (Brekke 2011). In this section I introduce the concepts of biosociality and biological citizenship, and discuss how they have been applied in the health literature and their relevance to my research.

Biosociality

Anthropological discussions of the formation of active patient groups have tended to draw on the concept of 'biosociality', a term formulated by Paul Rabinow in the mid-1990s (Gibbon & Novas 2008). Biosociality refers to the formation of social groups linked to a biological identity such as ill health or a susceptibility to ill health. However, Rabinow's term biosociality adds greater complexity to traditional patient groupings based on age, gender and ethnicity. Biosociality conceptualises the link between the emergence of new patient groups and identities and changing practices of science and medicine (Rabinow & Rose 2006).

Rabinow's concept was derived from ethnographic research undertaken on the Human Genome Initiative, a project sponsored by the United States' National Institutes of Health and the Department of Energy and mandated to produce a map of human DNA. He argued that this was the most potent site of new knowledge and power with the object of knowledge – the human genome – being knowable, and once that knowledge was acquired, *changeable* (Rabinow 2008: 236 emphasis, original). Rabinow's ethnographic question, therefore, concerned how our social and ethical practices would change as the project advanced. Rabinow proposed that this question could be answered at a number of levels and sites: the Human Genome Initiative itself; adjacent enterprises and institutions, namely the biotech industry, through which new understandings, practices and technologies of life would materialize (Rabinow 2008).

Rabinow proposed that biosociality - the formation of new groupings, identities and practices – would result from these developments in the new genetics:

> There will be, for example, neurofibromatosis groups who will meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on – and that is what I mean by "biosociality". I am not discussing some hypothetical gene for aggression or altruism. Rather there will be groups formed around the chromosome 17, locus 16,256, site 654, 376 allele variant with a guanine substitution. These groups will have medical specialists, laboratories, narratives, traditions and a heavy panoply of pastoral keepers to help them experience, share, intervene in and "understand" their fate (Rabinow 2008: 244).

Originally, the concept referred to new identities and practices emerging as a result of developments in genomics research, but over the past 15 years, since the introduction of the term, biosociality has been applied more loosely in scholarly work on how the practices of science, public health and medicine shape the formation of new identities For example, Guell (2011) applied the concept of biosociality to an ethnographic exploration of how Turkish Berliners organised themselves in a self-help group to understand, negotiate and even profit from having diabetes. Diabetes, Guell argued, may not seem an obvious choice in the context of biosociality given that the technologies at work in diabetes – blood glucose meters and other diagnostic tests – are less 'high tech' and 'high profile' than the genetic technologies at work in conditions such as Alzheimer's and cancer where the concept is more usually applied (Guell 2011: 378). Yet, Guell argued that 'biosociality' emerges without the presence of 'high tech' technologies. The Turkish Berliners in her study formed socially and politically organised and active self-help groups concerned with their diabetes, as well as the social inequality and deprivation that they experienced as a migrant population group at the margins of German society.

Whilst biosociality is a potentially useful concept for exploring practices of user involvement, and a theory which has been applied more recently by anthropologists in less high tech, non-genetic contexts (see Guell 2011), a related concept, biological citizenship, may be more meaningfully applied to the context of my research: stroke user involvement. I now turn to discuss this concept.

Biological citizenship

In 2002, Petryna published an influential text charting forms of scientific cooperation and political management that emerged in the aftermath of the Chernobyl nuclear disaster in 1986. She coined the phrase ‘biological citizenship’ to refer to the practices undertaken by Chernobyl plant workers and populations who mobilised around their claims of radiation-induced injuries (Petryna 2002; 1999). Through extensive ethnographic fieldwork undertaken in Ukraine, Russia and the United States over a five-year period and numerous interviews with plant workers, scientists, and clinicians, Petryna argued that the ‘damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims’ (Petryna 2002: p.5).

The concept of biological citizenship sheds light on practice of polity building and how nation states find legitimacy in people’s lives. Although Petryna’s work focused on a post-socialist context, the concept has relevance to other contexts where questions of interest concern emerging relationships between citizens and the state through policy implementation.

Rose and Novas (2005) also stake a claim to the term biological citizenship. Their development and thinking about the term began in 1999 (Rose 2007: 284) and refers to a new kind of citizenship taking shape in the age of biomedicine, biotechnology and genomics. They refer to ‘citizenship projects’ – the ways that authorities think about individuals as potential citizens and the means to define them. For example, authorities define citizens through a number of mechanisms: those entitled to participate in local politics; obliging citizens to speak a single common language or participate in a national, compulsory educational system; the design and planning of buildings and public spaces to encourage certain ways of thinking, feeling and behaving. Biological citizenship is used descriptively, to encompass all citizenship projects that link ideas of the ‘citizen’ to beliefs about the biological existence (Rose & Novas 2005). Biological citizenship can be understood as operating from above with authorities making and shaping citizens, or from below as aspirations of citizenship shape the way individuals understand themselves and relate to one another. Thus, Rose and Novas’ term has a wider, more general meaning, whilst embracing the specific definition offered by Petryna.

While groups organized around specific medical classifications have existed for quite some time, Rose and Novas argue that it is the increasingly specialized scientific and medical knowledge of one’s condition that transforms such groups into significant actors in the sphere of decision making about health. Furthermore, they argue that there are some novel features of biological citizenship in the current age, concerning different ideas about the role of biology in human worth, biological responsibility of the citizen, and the role of technology and how it intervenes upon the body.

Application of the concepts of biosociality and biological citizenship

Biological citizenship allows for an emergence of biology as the grounds through which citizens frame their demands on the state and civil society and create new forms of collective action or define their social membership. Biological citizenship can be linked to a number of processes and phenomena which have relevance to the policy and practices of user involvement. Biological citizenship speaks to a range of illness-based health social movements mobilising around environmental health, cancer, HIV/AIDS and mental health. It is linked to an increasing distrust of scientific and medical institutions on the part of citizens, and has associations with risk based society and the biological responsibility of citizens. Biological citizenship with its focus on biologically defined identity, at the individual and collective level, resonates with the policy and practices of user involvement, whereby patients are encouraged by professionals to define themselves according to a given biological status or a propensity or risk for that biological status.

Reubi (2010) uses the frameworks of biosociality and biological citizenship to explore the development and modernisation of Singapore post-independence. The Singaporean government promoted the ideal citizen, nation building and modernisation through the image of ‘the blood donor’ who gave blood through the Singapore Blood Transfusion Service (SBTS). ‘The blood donor’ was constructed as someone who was patriotic, contributed to the creation of a new nation state, and through providing their blood to help others was acting in solidarity with their fellow citizens. The blood donor therefore, was a citizen who was complicit and active in the development and modernisation of the nation ‘to build a better Singapore’ (Reubi 2010: 478). Whilst Reubi provides an example of biological citizenship from a different historical, geographical and biological perspective than that depicted by Rose (western settings, biological understanding at the molecular level), his argument is based on historical analysis of documents and may not reflect how Singaporeans themselves defined their citizenship, biological or not.

Robins (2008) applied Petryna’s definition of biological citizenship to explore how relationships between citizens and the state are being redefined in the context of struggles over access to HIV/AIDS health care and welfare in South Africa. He identified new forms of 'health citizenship' emerging through HIV/AIDS activism. These forms of citizenship were concerned with rights-based struggles for treatments and health services as well as creating collectively shared meanings of the extreme experiences of illness of people living with HIV/AIDS.

Robins situates his research in a context of public health fears of non-adherence to treatments and calls from public health practitioners for ‘responsibilized citizens’, knowledgeable and empowered HIV positive patients who will adhere to treatment regimens. Thus, Robins extends the concept of biological citizenship to ‘health citizenship’ or ‘responsibilized citizenship’, whereby changes in subjectivity produce the kinds of ‘responsibilized citizens’ that public health professionals believe are required for effective HIV treatment and drug adherence (2008:321).

However, Robins argues that a limiting factor of social movement and citizenship theoretical approaches to understanding changes in subjectivity is their neglect of the role of the illness experience and how this may transform subjects into 'responsibilized citizens' (Robins 2008). Robin’s puts forward Turner’s analysis of the ritual process as an approach which allows for a more complex and nuanced understanding of illness and treatment experiences and how this may transform citizens into responsibilized citizens. Robins' observation of 'treatment testimonies' illustrates the interplay between the social consequences and emancipatory possibilities of anti-retroviral therapy (ART) with individual experiences of the passage from ‘near death’ to ‘new life’ encompassing religious, communal and rights-based responses to these traumatic events which can transform HIV-positive people into both committed activists and ‘responsibilized’ citizens (Robins 2008: 321).

Kim (2012) and Fraser (2010) explore the frameworks of biological citizenship in the context of marginalised or disenfranchised patient groups. Kim (2012) explores ‘disenfranchised citizenship’ through South Korean immigrants in the United States (US). The research participants were primarily self-employed business owners who had no access to health services due to their lack of health insurance. Kim argues that in the US health insurance creates barriers to care and conditions differential access to biological citizenship. Kim argues that studying biological citizenship ignores those who are disenfranchised by the definitions and structures which create and bestow citizenship. Therefore, when we investigate biological citizenship we must commit ourselves to studying the consequences of those who are excluded, or disenfranchised, from this identity (Kim 2012).

Fraser (2010) conducted research with Hepatitis C patients in Australia to investigate the theory of biological citizenship in the context of patient encounters with medical knowledge. Fraser’s work explores different ways of engaging with medicine and different degrees of biological citizenship through interviews with individuals who acquired Hepatitis C through injecting drug use. She found that a focus on biological citizenship may lead us to overlook social factors more salient than disease, such as unstable, inappropriate housing and unemployment. An interview with one individual illustrated that once these factors had been resolved through non-medical intervention disease management, and biological citizenship, could become more of a priority. In another case, encounters with medical knowledge and adopting a biologically based citizenship resulted in an increased ability to critique producers of biological knowledge and the health systems and professionals which promote that knowledge.

Thus Fraser’s work questions the assumption made about the value attributed to engaging with health care and questions the assumption that it is biological identity which is the most salient. Her research illustrates that engaging with medicine has little benefit for Hepatitis C patients who need support with housing situations and employment prospects. Her work further questions the limitations of Rose’s concept of biological citizenship for those who fall outside of the model of responsible citizen and that people may resist being biological citizens.

3.3. Conclusion

In this chapter I have discussed two theoretical frameworks – three dimensional view of power and biosociality/biological citizenship – within which to ground the analysis of my empirical data. Both frameworks, whilst significantly different, offer novel lenses through which to view the implementation of user involvement policy.

I have presented the case for applying Lukes' three-dimensional view of power to the two empirical settings investigated in this thesis. Lukes' theory has been applied in many empirical situations, but has yet to be applied in the context of user involvement. The strength of applying Lukes' framework for understanding power in the context of stroke user involvement is to explore why acquiescence may prevail and change may be hard to foster.

I then presented an additional framework – that of biosociality and biological citizenship which may help to answer questions exploring how policy implementation creates new subjectivities and practices and if citizenship and identity determined through biology engenders new spaces and opportunities for contesting medical and scientific authority as some authors have suggested (cf. Orsini 2008; Klawiter 2008).

Referencing Bourdieu, Cowden and Singh (2007) argue that it has always been those with the greatest amount of ‘cultural capital’ who have historically obtained the best quality services from the welfare state. Although their argument is not grounded in empirical data, they argue that this pattern is repeated in the context of user involvement policy:

> the consumerist model of ‘User Involvement’ New Labour have adopted so enthusiastically effectively empowers those who expect to get the most in the first place, at the same time as it disempowers those with the lowest expectations (Cowden & Singh 2007: 17).

As I embarked on the empirical research, questions were raised concerning patient empowerment as an outcome of the policy. It became apparent that service users who involved themselves in service development or research were already empowered to some degree. How then, if the policy goals are to be achieved, do we ensure that those citizens who are not empowered become empowered? I began to wonder that if patient empowerment is a central concern of the policy, was user involvement the most effective mechanism to achieve this aim? Authors such as Orsini (2008) have made similar links regarding biological citizenship and its emancipatory potential. In my thesis I will apply biological citizenship as a lens through which to consider empowerment within the user involvement implementation process.

In the next chapter, I turn to the particular methodological approach taken in this thesis to address the questions raised so far.

Chapter 4: Methods

The research conducted for this thesis set out to investigate how professionals and patients interpreted and enacted a policy requirement to involve patients in service development and research. An ethnographic approach, entailing participant observation, seemed the most appropriate approach to take, given that the strength of ethnography is to observe what people do rather than just what they say they do, as might be revealed in a solely interview-based study.

In this chapter, I present a discussion of the methods used in this thesis to examine user involvement policy in stroke service development and stroke research, as put into practice in the two settings seeking to implement this policy. First, I discuss the use of anthropology and the ethnographic approach in health services research, and the justification for taking this approach in this study. I then give an overview of the study before describing in detail each of the methods used – participant observation, interviews, and collection of documentary evidence and quantitative data – and how I analysed the data collected. In the final section of this chapter, I discuss and reflect on the some of the ethical and methodological challenges of conducting ethnographic research in the two settings.

4.1. The ethnographic approach

In the 1950s, medical anthropology began to play a role in public health and health interventions. Anthropologists were seen as ‘cultural brokers’ particularly in developing countries where western governments or aid agencies were attempting to improve public health through health interventions. (Joralemon 2006;Pool & Geissler 2005). Since then medical anthropology has emerged with an increasingly important and critical, rather than complicit, role in recognition of health and disease as social and cultural phenomena as well as a biological phenomenon; and consideration of the political and economic forces that influence disease patterns and affect access to health care resources (Sargent & Johnson 1996).

Ethnography, the defining methodological approach of social anthropology (Savage 2000), is now widely used in applied anthropology and sociology (Ervin 2000) and has been successfully adopted, advanced and incorporated into other disciplines (Hastrup 2005), including public health and health services research (Balshem 1993; Day 2007;Huby *et al.* 2007). Literally, ethnography means a description of a people or an ‘ethnic’ group, but the word has multiple meanings and can refer to what the researcher does in the field, the actual fieldwork upon which the ethnography is based, and the text (book or report) produced by the ethnographer (Pool & Geissler 2005). The main techniques of ethnography are entering a specific setting, immersing oneself in the field, getting to know, and interacting with the people in the field through participant observation and key participant interviews (Emerson *et al.* 1995;Seymour-Smith 1986).

An important aspect of the main method of ethnography, participant observation[6], which marks it out from other research methods, is that it differentiates between what people say they do and what actually happens in practice (Brink & Edgecombe 2003;Lambert & McKevitt 2002). The ethnographic approach makes this distinction by '"situating" an interviewee's statements and the circumstances of the interview in the broader context of that person's life' (Lambert & McKevitt 2002: 211). For research studies such as mine, this approach allows the researcher to reveal, through the data, what actually happens in practice during policy implementation.

A further strength of the ethnographic and anthropological approach is that it enables the researcher to explore the nature of a phenomenon rather than assuming that it is unproblematic or focusing only on exploring the beliefs surrounding it (Lambert & McKevitt 2002). Consequently, in recent years ethnography has become increasingly popular as an approach in health services research to understand how health services operate, and behaviour and beliefs around health care delivery (Atkinson 1993;Huby *et al.* 2007). In public health and health services research, ethnography is 'particularly

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[6] There is an ongoing debate about the precise nature of participant observation - whether it is a method or a methodology and the implications this will engender for the researcher's involvement in the study setting (see Savage 2000a).

useful in understanding the organisation of health care' and to 'identify ground breaking questions or hypotheses that can be further explored through other methodologies' (Savage 2000: 1402). Allen *et al.* (2004), for example, used an ethnographic approach to explore resource allocation processes in stroke rehabilitation. The analysis of ethnographic data revealed that when access to funding was not problematic, health and social care professionals were able to collaborate effectively to meet stroke survivors' individual needs. However, where funding resources were restricted, collaboration was difficult to achieve. As a result, this had a negative impact on stroke survivors' and their families' individual preferences for care, despite policy imperatives for health and social care professionals to employ 'joined up', collaborative working practices. This ethnography demonstrated that policy imperatives alone may do little to achieve equitable resource allocation particularly when funding resources are restricted (Allen *et al.* 2004).

Hart *et al.*'s (2005) ethnography of a novel rehabilitation intervention for older people illustrates the multiple meanings that an intervention can generate, depending on which participant's view is considered. In this example, the rehabilitation intervention was viewed positively by managers and rehabilitation staff as they believed the scheme met the goal of enabling older people to return home after hospital and provided a new 'culture' or way of thinking about the capabilities of frail, older people. However, while some of the older people were positive about the scheme as it ultimately enabled them to return home, others had negative feelings towards it as they did not share the goal of returning home or felt that the prescriptive nature of the intervention deprived them of their freedom (Hart *et al.* 2005).

As I have suggested earlier in the thesis (see Chapter 1, section 1.1), the concept of user involvement is ill-defined and there is little research demonstrating how policy imperatives to involve service users are interpreted and enacted by participants (both service users and professionals). This makes the ethnographic approach particularly well-suited to explore the meaning of user involvement, and equally ill-defined associated concepts such as power and empowerment. The next section briefly describes the study where the ethnographic methods were applied.

4.2. Study overview

The research was undertaken in two enterprises where professionals had been charged with implementing Department of Health (DoH) policy to involve stroke survivors and their relatives in:

- the development of local stroke services –The Transforming Stroke Services Project (TSSP);
- public health research into stroke – the Stroke Research Program (SRP).

Detailed background on the two enterprises and the geographical area and community within which they were situated is provided in Chapter 5. The process of establishing and implementing user involvement was observed in order to understand how the policy was interpreted and understood by participants and how the policy transformed relations between professionals and patients. Immersion in the field was over three years (see Figure 4.1). From December 2004 to December 2007, I collected data on user involvement in the Transforming Stroke Services Project (TSSP). From January 2005 to January 2008, I collected data on user involvement in the Stroke Research Programme (SRP). The length of time spent in the field permitted observation of participants' responses to user involvement policy as they evolved over time.

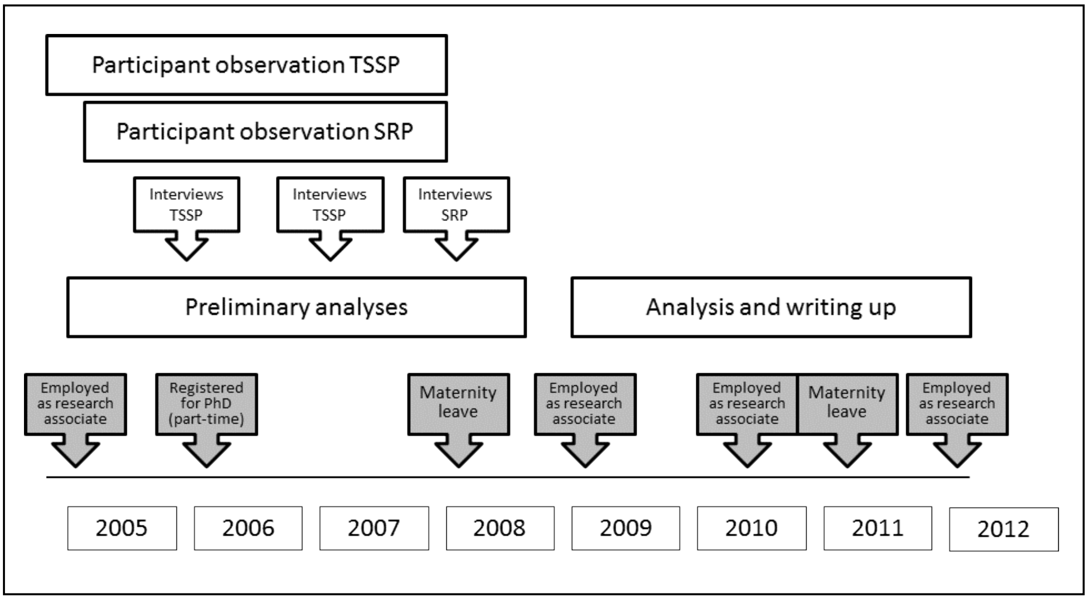

Figure 4.1 The research process

Participants

Study participants were drawn from those participating in stroke service development or stroke research. Participants fell into three categories: stroke survivors and their relatives; TSSP personnel (NHS managers and administrators, stroke clinicians, and voluntary sector staff); and SRP researchers. The location of both research settings within the same geographical field meant that some participants, predominantly stroke survivors and their relatives, participated in both settings (Chapters 5-7, and Appendices X and XI give more details on the research participants).

Ethical Approval

Ethical approval was sought from St Thomas' Hospital Local Research Ethics Committee in August 2004. Approval was granted in October 2004. In August 2005, an amendment to the ethics approval was sought to change the consent forms to incorporate a format which was more acceptable to research participants who had aphasia[7] after their stroke (this is discussed in greater detail in section 4.5 of this chapter). Approval to this amendment was granted in August 2005. The study was sponsored by King's College London.

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[7] Aphasia is a communication disability following brain injury, including stroke.

4.3. Data collection methods

The following section describes in detail the methods for collecting and recording data for participant observation, interviews, and the collection of documentary evidence and quantitative data.

Participant observation

In terms of the activities I undertook to collect and record data, I took a similar approach to participant observation in both enterprises where I was investigating the implementation of user involvement policy. However, locating and gaining access to each project, and my role as participant observer differed within each project. This was due to the diverse set-up of the two enterprises and my relationship to them: an outsider participant observer in the TSSP; an insider participant observer in the SRP. I therefore first outline my approach to undertaking participant observation in the TSSP, before addressing the approach undertaken in the SRP.

Participant observation in the Transforming Stroke Services Project

In 2004, a three year project to improve and develop stroke services in the two boroughs of Lambeth and Southwark was initiated. This project provided the setting for fieldwork and data collection on involving stroke survivors in stroke service development. Within the TSSP, observation, data collection and recording took place at over 62 meetings, and numerous events and informal face to face and telephone conversations. Participant observation entailed working with project personnel while remaining formally external to the project, undertaking administrative tasks, and attending and helping out at project events and meetings. I mainly attended meetings where user involvement was the focus of the meeting or where stroke survivors and their relatives were present, although on occasions I was invited by TSSP professionals to meetings where user involvement may not have been the main focus. Access to TSSP meetings was easily gained as these meetings tended to be run by Jackie, the User Involvement Lead, with whom I worked closely.

The types of meetings I first attended were those concerned with recruiting stroke survivors to be involved in the project. Later, I participated in specific ‘user involvement’ groups, attended by stroke survivors and one or two TSSP professionals, established to address some of the particular service improvements identified by the TSSP. During the second year of data collection, a need to embed user involvement more widely throughout the project meant that strategies to implement user involvement and progress made were discussed at monthly TSSP update meetings which I attended. This gave me the opportunity to observe how TSSP professionals who did not have a direct responsibility for user involvement, and with whom up until then I had had little contact, viewed and interpreted the project’s remit to involve stroke survivors in the transformation of stroke services.

Aside from meetings, much of my time was spent time at the TSSP offices helping out with administrative tasks such as entering stroke survivors’ details onto a database, telephoning stroke survivors in advance of meetings to remind them of the meeting and to check transport arrangements were in place. Ellen suggests that ‘many anthropologists find it necessary to find a regular task which is comprehensible to their informants under the auspices of which they are able to conduct their research' (Ellen 1984, p.112-3).The tasks I performed in the TSSP therefore were intelligible to those working in the TSSP and justified my participation in the project, allowing me to undertake participant observation.

I did not, and could not, attend all the meetings taking place within the TSSP. Alongside the specific user involvement meetings, other meetings and activities took place, such as meetings about developing a Transient Ischemic Attack (TIA) clinic, improving the environment of the stroke unit, and developing telemedicine. Although I was aware of these meetings, I did not directly participate in them. Time constraints and the inability to be present and observing in two places at once made undertaking participant observation at all the meetings within the TSSP unfeasible. Another factor, which prevented my full participation throughout the project, was that another research team was evaluating the TSSP as a whole, interviewing participants and observing and participating in meetings during the same time period as I was undertaking my exploration of user involvement. I sensed that the presence of too many researchers in a meeting would lead to TSSP participants feeling they were being over-researched. I therefore chose to participate and observe in meetings directly concerned with user involvement and stroke survivors.

For professionals working on the TSSP, I was probably somewhat of an outsider. Although I was not directly employed by the TSSP, there were close connections between the university and the hospital within which the TSSP was based, with the SRP providing data to the TSSP to support some of their activities. Stroke survivors saw me as a worker on the TSSP, even though I introduced myself as a researcher working at the university. Stroke survivors would class me with the other project workers, commonly saying, ‘You are all doing a fantastic job with this project’. During my time in the TSSP, professionals would often ask for my opinions on user involvement and for ideas about how to ‘take user involvement forward’ or to solve problems that arose during implementation of user involvement. For example, as people were aware that I was undertaking a PhD looking at user involvement, I was asked to give summaries of the literature on impact and status of user involvement in other health service settings to generate ideas for developing user involvement in the TSSP.

Participant observation in the Stroke Research Programme

Participant observation in the second setting was carried out within an ongoing stroke research programme in a department of public health at King’s College London. Participant observation was undertaken through over 44 meetings, and informal face-to-face and telephone conversations. When I began working at the SRP, there were no mechanisms in place to involve stroke survivors in stroke research, with the exception of some early attempts at what was then labelled ‘consumer’ involvement (this is discussed in greater detail in Chapter 5, section 5.4). My responsibility, under the guidance of the Principal Investigator (PI), was to establish user involvement within the research programme. This entailed researching and agreeing upon the kinds of user involvement activities and practices to undertake, contacting stroke survivors to participate in these activities, and encouraging stroke survivors and stroke researchers to participate in user involvement activities. Participant observation, therefore, entailed carrying out activities to implement stroke survivor involvement as well as observing these activities and the informal discussions and meetings between researchers about how to involve stroke survivors in stroke research. Once the process of how stroke survivors were going to be involved in the SRP was agreed, I took notes on how this was implemented. Once involvement, through the mechanism of a ‘research advisory group’, had been established, observations of the activities I undertook were recorded in the run-up to the meetings (for example, calling members to remind them about the meeting, discussing the meeting with researchers who were going to be in attendance to present their research) and during the meetings themselves. The SRP holds a meeting for stroke researchers every two weeks to discuss the business of the team and for researchers to present work in progress or completed research. I used these meetings as a further opportunity to take notes on the team’s attitudes to, and perceptions of, user involvement and how we should be involving stroke survivors in the research programme.

Consent and data collection

When stroke survivors, or relatives/carers of stroke survivors, joined the TSSP, they were asked to fill in a form for the User Involvement Database. This form collected participants’ contact details, basic demographic information, and the areas of the project they were interested in getting involved in. The form mentioned the research I was conducting and asked for participants to consent to be contacted at a later date to take part in an interview.

The membership of meetings on the TSSP was constantly changing, so every meeting tended to start with introductions. This gave me the opportunity to explain what I was doing and that I would be taking notes on what was discussed at the meeting for my research. This is illustrated by an extract from my fieldnotes:

> Jackie suggested that everyone introduce themselves since there were some new people and since this was the first time the information and training groups had worked together. When it came to my turn to introduce myself I said that I worked at King's College London, the university, and I was doing research to look at the ways of involving people who have had strokes, their carers and relatives in improving stroke services.
>
> Fieldnote, Joint meeting of Training and Information Groups, Tuesday 14th June 2005

On the SRP, a smaller more constant group of people were involved, so introductions were not necessary at every meeting. I formally explained the research I was undertaking in the first few meetings and reminded people about the research through the course of data collection. As part of the induction process to inform new stroke survivors about the involvement activities undertaken in the SRP, I explained about the research I was conducting to understand user involvement practices.

I kept detailed fieldnotes of each meeting, event and discussion I participated in and observed in both settings. Handwritten 'jottings' made in the field were written up into full fieldnotes on a computer as soon as possible after leaving the field and returning to my desk (Emerson *et al.* 1995: 51). Fieldnotes were stored as Word document files. I kept a reflective diary of my own behaviour, attitudes to the research, and thoughts and ideas I developed throughout the research.

During a period of observation, for example during a meeting, I took notes on everything that was said and done. I recorded all the topics that were discussed, stories that were told, who was seated where, emotions expressed, and what others were doing whilst others were talking (e.g. dozing, having private conversations). In the more general meetings, where user involvement was not the primary focus of the meeting, I took less detailed notes on episodes which appeared not to be relevant to my research questions, e.g. complex discussions on a model of patient pathway of service utilisation.

I observed and took mental notes of what happened and what was discussed by participants either side of formal meetings and included these when I wrote up the fieldnotes in full. The typical format of a meeting involving stroke survivors in both settings was for people to arrive up to thirty minutes before a meeting started. Those who had arrived would be made a cup of tea or coffee and we would sit round chatting whilst waiting for everyone else to arrive. After the meeting had finished, there were further episodes of 'hanging around' whilst people's taxis turned up (or failed to turn up) and this provided further opportunity for tea and chat. I often had to remember what occurred in these more informal settings as it did not feel appropriate to be taking notes during these conversations I was having with people either side of the formal meeting. In addition, I was often helping out with signing people into the meeting, making teas and coffees, and taking people's coats, so the presence of a notebook and pen would have impeded my role as a participant.

As well as collecting data and undertaking participant observation specific to the two settings, I was aware of the need to locate data collection and subsequent analysis in a wider context (Pool & Geissler 2005). Hansen (1997) notes the need to include different sites or levels in the observation of the policy process in order to grasp the complexity of how policies are discussed, articulated and implemented. I therefore observed and collected data at events I attended beyond the two settings. For example, throughout data collection and writing up of the thesis, I attended a number of conferences and seminars where user involvement was discussed and debated (see Appendix I and Figure 4.2). On these occasions, I took notes on the debates taking place, the topics under discussion, and the types of people attending the seminars and their views and attitudes to involvement. These contextual data were recorded as brief notes or memos in my journal to provide context and aid analysis.

Figure 4.2 Catharine and I setting off to a user involvement conference

Interviews

Throughout the period of data collection, I conducted interviews with participants to supplement the observational data. Two types of interview were conducted – informal and formal. Informal interviews took place on an ad-hoc basis. After a meeting, something may have occurred to me which I would try to clarify by engaging in discussion with participants – or sometimes participants would engage me in discussion. For example, after a particularly tense TSSP Management Group meeting, one stroke survivor engaged me in a frank discussion about his views on user involvement. In the SRP, researchers would approach me to discuss plans to present their research to stroke survivors. These discussions would lead to general discussions about user involvement – the implications for research and researchers, difficulties in implementing, and questioning what it actually achieves. These informal discussions were written up from memory after the event as part of the observational fieldnotes as it did not seem appropriate to be taking notes during a conversation.

Formal interviews differed from informal interviews as they were planned in advance, participants were selected for interview, and the topic guide (see Appendices II-VII), on which the interview was based, was prepared in advance. Table 4.1 and 4.2 detail who was interviewed and the purpose of the interview for interviews undertaken with the TSSP and SRP respectively.

Table 4.1 Formal Interviews undertaken in the Transforming Stroke Services Project

Date of interview	Involvement status at time of interview	Number of participants	Purpose of interview	Type of interview
August 2005	Attendees at an involvement event who subsequently declined to participate further	6 stroke survivors 1 relative/ informal carer	To understand what people who did not want to participate thought about user involvement and the reasons why they chose not to participate	Telephone n=5 Face-to-face n=2
March - April 2006	Participating	7 stroke survivors 2 carers 3 health care professionals	To understand what user involvement has been like for those who chose to participate. Interviews with stroke survivors focused on their stroke story, current activities and hobbies, barriers and facilitators to their involvement, and what they thought of policies to involve patients in service development.	Telephone n=1 Face-to-face n=11

Table 4.2 Formal interviews undertaken in the Stroke Research Programme

Date of interview	Involvement status at time of interview	Number of participants	Purpose of interview	Type of interview
September 2007	Participating	7 stroke survivors 3 relatives/ informal carers	To reflect on the progress of the research user group over the two years since its inception. To understand what user involvement has been like for those who chose to participate, why they chose to get involved, what they saw as their influence on the SRP.	Group discussion
December 2007 – January 2008	Participating	4 stroke survivors 7 researchers	To understand participants' views of participating in the research user group, what they saw as their influence on the SRP, and the implications of the research user group for research processes.	Face-to-face n=11

Nineteen interviews with participants involved in the TSSP were conducted. I conducted the first set of interviews with stroke survivors and carers who had attended a user involvement event, but who then declined to be involved further (for interview topic guide see Appendix II). Five of the seven interviews were conducted over the telephone. I decided to conduct telephone interviews since I did not want to intrude too much in the lives of people who had said they wanted no further involvement in the project in the first place. These people indicated that they would only consent to a quick telephone interview and were less keen to commit to a longer face-to-face interview. For example, one female participant said that she was ‘willing to answer my questions as long as it didn't last too long’.

About a year after user involvement had been implemented in the TSSP, I conducted interviews with health care professionals and stroke survivors, and carers who had participated in the user involvement groups that the project had established. All the interviews, except for one, were conducted face-to-face, usually in the participant’s home or place of work. In one interview, the participant’s daughter arrived at the beginning of the interview with the weekly shop. She made coffee for the participant and me and then joined us and took part in the interview. One interview was conducted over the telephone because the participant was too busy to give her time for a face-to-face contact. I purposively selected people to represent a cross section of the group involved: male/female, different age ranges, severity of stroke. I used a topic guide (see Appendices III and IV) to guide the discussion with all the interviews, but I allowed interview participants to raise their own questions or topics which they felt were important to discuss. The topic guides were based on my research questions, themes that had arisen in the observations for which I needed clarification and the literature focusing on user involvement, empowerment and power.

In the SRP, I held one group discussion with stroke survivors involved in stroke research about the nature of their involvement and formal interviews with four stroke survivors and seven researchers. These were conducted towards the end of the period of participant observation, after user involvement had been established for two years. I chose to hold a group discussion to reduce the amount of time needed to interview everyone separately. The PI and I felt that there would be value for the group to take part in a group discussion for themselves as well as for the research. The group discussion took place almost exactly two years after an initial meeting with stroke survivors to determine how they could be involved in stroke research. We felt that it would be valuable to discuss the development and progress of stroke survivor involvement in the SRP in a group setting, particularly as the majority of stroke survivors had retained their involvement in the SRP since the initial meeting (Fielding 1993). The group discussion was billed as a chance for us all to reflect on the past two years as well as for me to collect data for my PhD. There were 10 people present during the discussion, including the PI of the project and me. The PI initially led the discussion, based on a topic guide (see Appendix V) I had put together, but then the members of the group steered the discussion to the topics they wished to discuss. I followed up the group discussion with individual interviews with four participants who had either not been at the discussion or who were not vocal during the group discussion. These interviews were completed as face-to-face interviews in the participants' homes using a similar topic guide (see Appendix VI) as used in the group discussion.

I aimed to interview all the stroke researchers who had had contact with the Stroke Research User Group: excluding me, this included ten researchers. I decided not to interview three of the researchers (the project PI and two colleagues whom I was close to) because I had frequently discussed my fieldwork, research and thoughts on analysis with them, so thought this may have influenced their responses during an interview. Six researchers agreed to be interviewed and one declined. Another researcher in the team, who had not had direct contact with the user group but had taken part in a number of discussions about user involvement, asked me if he could be interviewed. The interview topic guide used with stroke researchers can be found in Appendix VII.

Consent and data collection

Interviewees were asked if they agreed to having the interview recorded and to sign a consent form, if they had not already given consent. Interviews, which lasted between 37 minutes and over an hour and a half, were audio recorded (using either audio tape or digital recording equipment) and fully transcribed. Where participants declined to be tape-recorded (n=4) or where telephone interviews had been conducted (n=6), detailed notes were made during the interview and written up as soon as was possible after completing the interview.

Documentary evidence

Throughout the research process, I have collected two categories of documents: 1) documents related directly to the two settings such as project aims, project reports and status updates, research grants, newsletters, minutes of meetings; and 2) documents to help situate user involvement in stroke in a wider context such as DoH policy documents on user involvement, newspaper articles, transcripts from the Public Accounts enquiry into public involvement, documents produced by Involve.

Quantitative data

I collected quantitative data on those participating, including: numbers of stroke survivors and carers invited to participate; numbers who decided to participate and how frequently they actually participated; and characteristics of those participating: age, disability after stroke, time since stroke.

4.4. Data analysis

Analysis in an ethnographic approach is not a distinct phase occurring after data collection. It is a continuous process occurring prior to data collection in the pre-fieldwork phase as research questions are identified, progressing as the ethnographer enters the field and begins participating, observing and collecting data. Analysis remains part of the process right through to the final writing of reports, and papers and books (Davies 1999;Emerson *et al.* 1995;Hammersley & Atkinson 1995). Although I have used a number of different data collection methods, and have ended up with a number of sources and type of data, with respect to analysis I have treated each type of data in the same way as they all form part of a whole.

Reflecting and interpreting on the data began as I was in the field making observations, and these interpretations and reflections were further consolidated and built upon during the writing up of the descriptive fieldnotes. During participant observation and writing up the day's jottings into fieldnotes, I would note down thoughts, feelings, reactions to, or questions about the descriptive text I was composing as *asides* or more elaborate *commentaries* (Emerson *et al.* 1995). An example of an aside is from the first meeting of the TSSP Management Group attended by stroke survivors. Prior to this, the TSSP Management Group had been meeting for a year without the presence of stroke survivors:

> Karen was chairing the meeting and profusely welcomed Kartik, William and me to the meeting as new members in the group. Looking at us, Karen profusely thanked us for coming. Again, at the end of the meeting Karen thanked us for attending the meeting and for our input (*I was beginning to wonder if she thought I was a stroke survivor too as every time she talked to the 'service users' she would look at me as well as Kartik and William. I thought that this is what it must feel like to be a service user in a group dominated by professionals – the profuse welcome and thanking, although I'm sure expressed with good intentions, felt slightly patronising and singled us out from the rest of the group).*
>
> Fieldnote, TSSP Management Group, Thursday 29th September 2005

In-process memos were written at the end of a session of writing up the day's observations. Emerson *et al.* (2005) define *in-process memos* as analytical thoughts and notes about the direction the research should take, what questions needed to be asked, what ideas should be followed up. I tended to write these analytical thoughts and notes in my journal. I wrote *in-process memos* after reviewing a series of fieldnotes. Every three months, I would review the fieldnotes, documents and interviews constructed during that quarter and write up the *in-process memos* in a separate Word document. Below is an example of a thought that occurred to me after reviewing a period of observations:

> Differences between service users – some of the literature promoting user involvement gives the impression that all users have the same views and are more understanding towards each other than researchers or professionals are. This hasn't necessarily been the case with the users involved in the TSSP. There has been strong disagreement with people's beliefs about why strokes happen, how the body is affected after a stroke, what causes high blood pressure and what services need to change. Certain groups of service user have aligned themselves towards professionals whose medical beliefs fit better with their own beliefs about what causes a stroke. They have wanted to distance themselves from the service users who in the formers' eyes don't understand how a stroke happens.
>
> Memo – summary of observations on Stroke Service Project, April – June 2005

In October 2008, I returned to my written fieldnotes for further analysis and to begin the process of transforming the fieldnotes into the ethnographic text. The original fieldnotes, interviews, and memos were stored in NVIVO 7 to aid data management. Analysis involved reading, elaborating and refining previous analyses by subjecting fieldnotes to close, intensive reflection and analysis (Emerson *et al.* 1995). Data were read and analysed in chronological order to give the sense of change over time. The data sources were read through iteratively to textually analyse and categorise the data according to predefined themes and sub-themes (*focused coding*). This additionally allowed for the creation of new categories as they emerged from the re-readings of the data (*open coding*) (Emerson *et al.* 1995).

Open coding focused on any and all ideas, themes, issues suggested by the data until no new themes emerged. *Focused coding* involved line-by-line analysis of the data on the basis of:

- themes of particular interest (ideas generated through *in-process memos* written at the end of writing up sessions and fieldnote reviews about the direction the research should take, what questions needed to be asked, what ideas should be followed up)
- the theoretical framework of the thesis (e.g. Lukes' three-dimensional view of power, empowerment, embodied health movements).

The same procedures for analysis were applied to all the data sources: observations, journal, interviews, and documents (Emerson *et al.* 1995). Documents underwent additional analysis to compare and contrast statements in documents with events and incidents I observed: how were the documents written? Who wrote the documents? Who was the audience of each document? Why were the documents written? What was recorded and what was omitted? (Hammersley & Atkinson 1995). Theoretical *integrative memos* were created to integrate the data and to clarify and link codes, analytic themes and categories (Emerson *et al.* 1995). These were created using a combination of pen and paper, sticky notes and whiteboards.

Finally, I set about constructing the ethnographic text to convey my findings to the reader. This consisted of an iterative process of writing and rewriting cycles as I tried to construct a text which would 'convince the reader of the authenticity and worth of my writing' (Van Maanen 1988, p. xi). Ethnographies are shaped by the specific disciplines and traditions from which the fieldworker originates and the narrative and stylistic conventions the writer chooses to employ (Van Maanen 1988). Ethnographic writing, therefore, ranges from the literary, novel-like texts to ethnographic texts used in ‘qualitative health research’ more influenced by the medical journal style of reporting. Van Maanen (1988) notes how the conventions of ethnographic writing have changed over time particularly with the growth of ethnographic practices in fields beyond anthropology’s traditional boundaries, such as political science, law, medicine, business administration, education, criminal justice, and policy studies.

4.5. Ethical and methodological challenges

Undertaking ethnographic and anthropologically informed research in a UK health care setting raises a number of unique ethical and methodological challenges which researchers using the same approaches in other disciplines may not face. In this section, I discuss some of the ethical and methodological challenges I faced in conducting participant observation in the two settings, namely making the settings and participants anonymous during the writing-up phase of the ethnographic process, applying consent procedures as defined according to a biomedical model of research to an ethnographic research design, and assessing the reliability and validity of the research I conducted. First, I will discuss the multiple roles I faced as a researcher conducting participant observation.

Positionality and the multiple roles of the researcher

The workplace has become an increasingly critical site of ethnographic enquiry (Prentice & Whitelaw 2008). When researchers are employees, or as in my case an employee and doctoral student, within the setting they are researching, the issues concerning access to the research setting are heightened. A number of authors have discussed the ethical dilemmas and points of contention arising when ethnographers have multiple roles and statuses in their fieldwork (Burr 2002;Knox 2005;Shuttleworth 2004). This is particularly the case when anthropologists, or researchers using an ethnographic approach, are employed in the organisation they are researching. The researcher becomes part of the community they are investigating. Their colleagues and supervisors become informants and research participants as the research process unfolds (Knox 2005;Mosse 2005;Prentice & Whitelaw 2008;Shuttleworth 2004). My insider/outsider status within the research process was further complicated by the fact that I was doing more than just observing the practices of user involvement as they unfolded. I was also partly responsible for how those practices unfolded as one of the 'professionals' responsible for implementing user involvement policy, particularly in the SRP.

I found my role as both participant observer, responsible for observing user involvement, and a researcher, partly responsible for establishing user involvement in the SRP, conflicting at times. As a 'member' of the user group, I wrote the minutes of the meetings which form part of my data for analysis. As a result, my own output becomes part of the material to be analysed.

> Thoughts on writing up the minutes from the user group – how will this impact on the research and evaluation? Are the power relations between researchers and people who have had a stroke reflected in my minutes? For example I don't always write up everything that the users said in the meeting, but I think I do write more of what the professionals have said in the meeting. This could however reflect the structure of the meeting which is run by C and me, despite our attempts to try to get the users to take on a more active role such as chairing the meeting.
>
> Diary entry, 21st March 2007

I have had to think critically about my actions as a researcher employed in the stroke research team and how these may have influenced the development of user involvement in the Stroke Research Programme. My needs and requirements as a contract researcher may have influenced how user involvement was established within the Stroke Research Programme and determined which areas stroke survivors were allowed to participate in:

> It is now a day after the meeting I had with the PI and the Head of the SRP about publications arising from the project. The Head of the SRP asked me if I planned to write any publications with the user group. I had said that we weren't planning to, but was I too quick to assume that the users wouldn't be interested in writing a paper? Were there other reasons why I might not want to write a paper with the user group? Would it take much longer to get something published the more people who are involved? Given that publication is a priority for researchers I am concerned that writing with the users would perhaps delay and jeopardise me meeting my required outputs. I have read a couple of papers which have been co-authored by researchers and users and they don't read very 'scientifically' and seem slightly patronising. Is this the real reason I don't want to write a paper with users? Having thought about this in more detail and discussed my attitude with another colleague I now feel that we should definitely ask them if they want to write a paper with us, perhaps the one about the cost of stroke study process. My colleague said that surely in the research I am doing I want to look at involvement through all stages of research and dissemination and writing papers is a stage of research that I should be considering.
>
> Fieldnote, 10th August 2007

In the TSSP, I was not responsible for making decisions about how stroke survivors were to be involved to the same degree as I was on the SRP. However, participants in the TSSP often asked for my advice or opinion and my responses may have influenced aspects of the project. In order to overcome these potential influences, I have made explicit the occasions where my actions or words may have influenced the project through my fieldnotes and the reflexive diary (Pool & Geissler 2005).

A risk of participant observation is that the ethnographer adopts a particular stance or rapport with a particular group of participants in order to gain access and trust (Hammersley & Atkinson 1995). Over-rapport can lead to problems in analysis if the ethnographer cannot sufficiently distance herself from participants' accounts.

Throughout the process of participant observation and data collection, I felt I had to take a particular stance on user involvement. In order to gain access to the TSSP and to be able to work closely with Jackie, I felt I had to adopt a positive attitude towards user involvement – that it was morally right for service users to be involved in decisions about services. However, in discussions with Jackie, I was able to express my reservations about the way the policy was promoted and the naive assumptions within the policy which made it hard for professionals to implement the policy, as she too held these conflicting views. Within the SRP, it was necessary to be positive about user involvement in order to encourage other researchers and stroke survivors to participate so that the user involvement could be established within the programme. The implication of this for the research will be discussed in the final chapter of the thesis, Chapter 9.

Making the data anonymous

I took the decision to not make the data completely anonymous. It would have been impossible to disguise where I conducted the research, given that I am a PhD student in the same place where I conducted part of the research. Those who were familiar with the SRP would have been able to deduce the service setting if I were to make that setting anonymous. Although I have not disguised the settings, I have kept the participants in the ethnographic study anonymous and given them pseudonyms. For those who are familiar with either of the two enterprises, it will be possible to work out who certain people are, particularly those who had central roles within each enterprise or in establishing user involvement. However, the decision to not completely disguise the identity of the field site and the participants within has helped with the process of analysis and writing up as it keeps in mind that as an ethnographer my 'task is to write description that leads to an empathetic understanding of the social worlds of others' (Emerson *et al.* 1995: 72). Scheper-Hughes revisits anthropological ethics and the difficulties of balancing 'responsibility to honest ethnography with care and respect for the people who shared a part of their lives and their secrets with [her]' (Scheper-Hughes 2001: xiii) in the preface of the twentieth anniversary edition of *Saints, Scholars and Schizophrenics.* In her original ethnography, written in the mid-1970s, Scheper-Hughes employed the convention of pseudonyms and 'careful' construction of composite characters to disguise community members and participants. However, on reflection, particularly in response to fierce criticism from the community who recognized themselves in her writing, Scheper-Hughes argues that the use of such devices 'makes us forget that we owe our anthropological subjects the same degree of courtesy, empathy and friendship in writing that we generally extend to them face to face in the field' (Scheper-Hughes 2001: 12-13).

Obtaining informed consent

The process of obtaining informed consent based on the traditional biomedical research study where the research subject signs a form is not always as easily applied with qualitative research (Murphy & Dingwall 2003). The process is further complicated with ethnographic research (Hammersley & Atkinson 1995). It was impractical and intrusive to obtain consent from all participants at large meetings and events where over 20 people were in attendance. In these situations, whilst I was not deliberately acting covertly, not everyone in the room may have been aware of my role as a researcher. In smaller group meetings or interviews with individuals, I had the opportunity to introduce myself, was able to explain what I was researching, and ask participants to sign a consent form.

However, on a couple of occasions I experienced hostile reactions from stroke survivors, who had communication problems as a result of their stroke, at my request that they sign a consent form. They found the heavily worded information leaflets and consent form, written using a traditional format approved by the ethics committee, threatening given that they could not read what was written and therefore could not be sure what they were signing. As a result the PI and I decided to redesign the consent forms using the style and format promoted by Connect – a communication disability network. The forms were redesigned to include a patient information booklet and a separate consent form (see Appendix VIII).

The booklet explained the purpose of the research, what being involved in the research entailed, and what the expected outputs of the research would be. The text was written in short sentences with key words highlighted in bold. Pictures were used to illustrate each point. The consent form was modified so that each point that the research participant was agreeing to was listed on a separate line, giving the participant the opportunity to clearly understand what they were agreeing to.

After using the redesigned consent form, I did not experience any further negative reactions from those with communication disabilities. However, one or two stroke survivors, whose communication ability was not impaired, have commented that they found the material slightly patronising. This raises the question of how to provide clear, understandable information to people with a range of communication abilities without making participants feel either threatened or patronised.

Reliability and validity

The increased use of qualitative methods in health research was followed by expressions of concern with how the quality of reports produced might be assessed (Seale & Silverman 1997). One response was the development of quality checklists, although this approach has been criticised. For example, it has been argued that the over-reliance on quality checks undermines the true value of ethnographic research in terms of substantive knowledge and theoretical concepts (Barbour 2001;Lambert & McKevitt 2002). LeCompte and Goetz (1982) recommend a number of strategies to be taken to ensure the reliability and validity of the ethnographic account.

Establishing reliability (that the same findings would be generated should the study be replicated by another researcher) of the data is complicated by the fact that ethnographic research is conducted in a natural setting, often to record processes of change. Ethnographic data are produced through the social relationship of the researcher with the participants in the setting. Therefore, LeCompte and Goetz recommend that research reports clearly outline the methods used to collect and analyse data, identify the researcher's role and status within the setting investigated, discuss how informants were selected and the social circumstances in which information was revealed by informants, and outline the theoretical premise informing the research (LeCompte & Goetz 1982).

Validity is concerned with the accuracy of the findings: do scientific researchers actually observe or measure what they think they are observing or measuring, and to what extent are the abstract constructs and postulates generated, refined, or tested by the researcher applicable across groups? Whilst reliability can be problematic, the approach to data collection in ethnographic research can ensure high levels of validity compared to other research approaches (LeCompte & Goetz 1982). The collection of data over long periods of time allows for continual data analysis and comparison to refine constructs and to ensure a match between scientific categories and participant reality. Furthermore, participant observation is conducted in natural settings that reflect the reality of the life experiences of participants more accurately than do contrived settings. Participant observation combined with immersion in the field should ensure that participants and informants do not change their behaviour in the presence of the researcher. Interviews with participants are more likely to use the terminology and empirical categories of the setting and consequently will be less abstractly formed than the instruments used in other research approaches. The reflexive nature of the research ensures that all phases of the research process are subject to continual questioning and evaluation (LeCompte & Goetz 1982). The application of these strategies is discussed in relation to the study findings in Chapter 9 of this thesis.

4.6. Conclusion

In this chapter, I have discussed the use of an ethnographic approach to answer the particular research questions of this thesis. I have outlined the methods I have used in this ethnographic study of user involvement and the methodological and ethical challenges of the data collection and analysis. In the following chapter I will set the scene by contextualising the wider policy context, the geographical location, the local community and the two settings where I conducted the research.

Chapter 5: The field of research

This chapter outlines the study field where I conducted the research. The concept of the 'field' is central to ethnographic inquiry. What constitutes the field, however, has changed over time with the modernisation and pluralisation of cultures. The field where this ethnography took place contrasts with classical anthropological notions of the field, typically a discrete, bounded, identifiable place such as a village. Contemporary anthropology has reconceptualised and extended its field of research, however, to incorporate the study of populations or groups of people through 'multi-sited' ethnography (Hannerz 2006;Hansen 1997;Marcus 1995). In contemporary ethnography, the field may incorporate material, physical, policy and organisational sites. Ethnography is now frequently conducted in interdisciplinary arenas such as media studies, feminist studies, science and technology studies, cultural studies, business studies and healthcare. Since these arenas do not provide clearly bounded objects of study, multi-sited ethnography is practised by necessity (Marcus 1995).

Hansen's (1997) ethnography of communication policy in an oncology department of a Danish hospital illustrates this reconceptualisation of the anthropological field of research. In this ethnography, Hansen applied a broad definition of the field that went beyond purely geographical descriptions of the hospital setting under study. Thus, the sites of participant observation in her ethnography included: the oncology department itself; the specific hospital policy document; the policy document as interpreted by the oncology nursing team; observations of doctor-nurse communication; and observations of nurses’ and doctors’ communication with patients; and the wider context of medical policy in Denmark in the 1990s as debated by patients, health care professionals, and journalists via various media (Hansen 1997).

In this ethnography, the field is similarly multi-sited: national policy on involving patients in health research and service design; NHS and academic enterprises where the policy was implemented; stroke survivors’ experience of stroke; and the wider context of lay expertise and challenge to experts. In this chapter, I first describe the two boroughs within which the research was undertaken from a geographical and historical perspective. I then focus on the community living within the two boroughs and discuss isolation, health and illness in general and then more specifically the case of stroke - how it is managed in the two boroughs, before ending with a discussion on the local and national policy context driving the ‘modernisation’ of stroke services. The final two sections of the chapter focus on the two enterprises attempting to establish user involvement where I conducted participant observation. I detail the background of each enterprise and how I entered and gained access to each enterprise. Both enterprises focused on stroke and stroke services, but from different perspectives: developing new or improving existing services in the case of the Transforming Stroke Services Project (TSSP), researching stroke and stroke services in the case of the Stroke Research Programme (SRP).

Although the two enterprises where I carried out participant observation were distinct, with their own remits, and differing responses to user involvement policy requirements, they were interconnected and overlapping. Both enterprises were situated in the same geographical area, within the boroughs of Lambeth and Southwark and shared the same population of stroke survivors as potential ‘service users’ to be involved in either enterprise, or in some cases both.

5.1. Lambeth and Southwark

The data collected for this PhD come from three years’ fieldwork undertaken in Lambeth and Southwark, two central southern boroughs of London. While I had not lived in London for a number of years prior to starting the research position at King’s College London (KCL), I was familiar with the research location as I had lived in Camberwell (a part of Southwark) whilst studying for my Master’s degree and working as a research assistant at a London university.

The boroughs of Lambeth and Southwark were formed in 1965 with the amalgamation of two smaller Metropolitan Boroughs of Lambeth, and Southwark, Bermondsey and Camberwell (McKenzie 1999;Reilly 1998). Both boroughs border the river Thames at their northern edges, extending southwards. The area has always attracted immigrants: the Huguenots and German immigrants in the 18th century; Irish immigrants in the 19th century; African, Caribbean and Asian immigrants after the Second World War (Boast 2000). Today, the population is multi-ethnic with greater diversity compared to other parts of the UK (see Table 5.1, overleaf). Lambeth and Southwark rank highly in scores of deprivation (unemployment, overcrowding, percentage of people living in non-owner-occupied households); most areas within Lambeth and Southwark are amongst the most deprived of England (APHO & Department of Health 2007a;APHO & Department of Health 2007b).

Table 5.1 Description of population of Lambeth and Southwark, compared with that of London and UK.

	Lambeth	Southwark	London	UK
Population*	266,170	244,867	7,172,091	58,789,194
Age structure*				
0-14 years	18%	19%	19%	19%
15-24 years	14%	15%	13%	12%
25-49 years	48%	44%	41%	36%
50-64 years	11%	12%	14%	17%
≥65 years	9%	10%	13%	16%
Ethnicity*				
White	62.5%	63%	71.2%	92.1%
Mixed	4.8%	3.8%	3.2%	1.2%
Asian or Asian British	4.6%	4.1%	12%	4.0%
Black or Black British	25.8%	25.9%	10.9%	2.0%
Chinese	1.3%	1.8%	1.1%	0.4%
Other	1.2%	1.5%	1.6%	0.4%
*Figures from 2001 Census www.neighbourhood.statistics.gov.uk				

As with other inner city parts of London, areas of Lambeth and Southwark were devastated by bombing raids of the Second World War. After the Second World War, thousands of people were in need of housing; there was a need to either replace homes destroyed in the war or continue slum clearance programmes that had begun prior to the war to improve living conditions (Boast 2000). Tower blocks rising skyward surrounded by public open spaces replaced closely-knit streets and small houses (see Figure 5.1, overleaf).

Figure 5.1 An example of tower block housing in Southwark

The policy of demolishing 19th-century properties and replacing them with modern estates continued into the 1970s. Although the intentions of architects and planners in 1960s and 70s had been to provide housing with light and space and with walkways to remove pedestrians from the danger of roads and cars, the reality was that the tower blocks were not ideal homes for families. The apparent safety measures of the walkway, for example, provided the threat of muggings (Collins 2004). Collins, perhaps providing a romanticised description of the white working class of Southwark in *The Likes of Us*, has argued that the transient, itinerant nature of new populations and lax management of the estates by councils brought in an ‘undesirable’ element to the population which long-standing residents believe has destroyed the community spirit

(Collins 2004)[8]. The area, particularly around Elephant and Castle and Peckham is undergoing a new wave of development; tower blocks are being replaced with new developments to address problems of city living, such as unemployment, low expectations, high crime rates and a poor environment which parts of Southwark have become solely known for (Southwark Council 2007).

Health and illness

As well as being two of the most deprived boroughs in London, Lambeth and Southwark have been portrayed in the London press as the 'sick boroughs' of London, inhabited by populations with future health problems.[9] The two boroughs are served by three large teaching hospitals: King's College Hospital, Guy's Hospital and St Thomas' Hospital, with prominent roles in the local community. King's College Hospital is located in the southern reaches of Southwark. At the time of fieldwork, Guy's Hospital tower dominated the skyline around London Bridge, the Borough and Bermondsey[10]. St Thomas' Hospital, affectionately known as Tommy's, occupies an enviable riverside location opposite the Houses of Parliament. At the time of conducting the research, Guy's and St Thomas' Hospitals featured in *City Hospital,* a

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[8] Historians, however, have argued that Southwark has had a long history of attracting 'undesirables' (Boast 1993;Boast 2000;Reilly 1998).

[9] 'London boroughs will be the worst for healthy living'. *LondonLite*, Friday 4 January 2008; http://www.timesonline.co.uk/tol/news/uk/health/article3129375.ece

[10] Illustrative of urban renewal and change, Guy's Tower is now dwarfed by a redevelopment of London Bridge. Once completed in 2012, the Shard, part of the development, will be the tallest skyscraper in Europe.

popular, long-running, weekday morning television programme on the BBC following the lives of hospital staff and patients.[11]

As with many parts of the UK, local NHS services and hospitals are frequently being reorganised and reconfigured, linked to NHS cost and efficiency drives from the Thatcher era onwards. In the early 1990s, Guy's Hospital was changed from an acute general hospital with an Accident and Emergency department to a hospital specialising in treatments which do not require an overnight stay. According to the Save Guy's Campaign, the history of health services in this area has been one of '25 years of closures and service reduction against promises of new services in different places to replace them' (Save Guy's Campaign 1994) .This trend looks set to continue following a 2009 review of the capital's stroke services (Healthcare for London 2009). This review led to the reorganisation of acute stroke care in London with the introduction of eight 'hyper-acute stroke units' to provide the immediate response to a stroke. The location of the eight HASUs across the capital was to ensure all inhabitants within the capital have equal access to specialist stroke care. This reorganisation of services will, however, see the end of acute stroke care role undertaken by clinicians in the stroke unit at St Thomas' Hospital. Once the service reorganisation is complete the St Thomas' Hospital stroke unit will perform a primarily rehabilitation role, once the acute stage of a patient's stroke has been managed (NHS London 2010). Once more,

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[11] http://www.guysandstthomas.nhs.uk/news/newsarchive/newsarticles/cityhospital.aspx

local people may have to travel further afield for the acute stroke services they require.

Over the period of my fieldwork, all three hospitals held open days attracting over 2000 visitors from the local community[12]. The open days, aimed at providing ‘fun for the family’, give the local community the opportunity to go behind the scenes to see the hospitals at work as well as providing entertainment such as a Victorian fun fair and musical acts. In 2007, the open day was held at Guy’s Hospital and, in conjunction with King’s College London, included information stalls highlighting medical research undertaken at the hospitals. I attended with some colleagues from the Stroke Research Programme to disseminate information about stroke research and the South London Stroke Register (SLSR). Although our stand was not as popular as some of the more interactive stalls, such as the minor injuries stall where children could get their arms bandaged, a steady flow of middle aged to older people enquired about the research and asked about stroke, with a number of people admitting they felt they were ‘at risk of stroke’.

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[12] http://www.guysandstthomas.nhs.uk/news/newsarchive/newsarticles/open_day_2007.aspx; http://www.kch.nhs.uk/news/archive/2008/kings-celebrates-60-years-of-the-nhs-and-attracts-record-visitors-at-its-annual-open-day/

Stroke in Lambeth and Southwark

Data from the SLSR indicate that as of 2002, for the northern wards of Lambeth and Southwark, stroke incidence rate per 1000 population was 1.33[13] (crude), 1.28[14] (European adjusted) (Wolfe *et al.* 2002). Of those surviving their stroke, 20%–30% of survivors had a poor outcome over ten years of follow up (Wolfe *et al.* 2011). Deaths from stroke in Lambeth and Southwark are higher than the national average (APHO & Department of Health 2006;APHO & Department of Health 2007b).

At the time of fieldwork, when someone had a stroke in Lambeth and Southwark, depending on where they lived, the severity of the stroke, and if the seriousness of the stroke has been recognised, they would usually be admitted to the emergency departments of King's College Hospital or St Thomas' hospital and then transferred to a stroke unit[15]. The stroke unit at St Thomas' hospital was one of the first such units in London when it was established over 19 years ago[16]. Both stroke units at the two hospitals provided acute care for the period immediately after stroke and rehabilitation care lasting days or weeks. Data from the SLSR for the period 2001 - 2004 show that 87% of people having a first stroke were admitted to hospital and 56% were transferred to a stroke unit (Smeeton *et al.* 2009). The length of time a patient will stay on the stroke unit will vary depending on the severity of the stroke,

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[13] (95% CI 1.26 to 1.41)

[14] (95% CI 1.2 to 1.35)

[15] This was the case at the time of data collection, but the system changed in mid 2010 with the introduction of Hyper Acute Stroke Units across London.

[16] http://www.guysandstthomas.nhs.uk/news/newsarchive/newsarticles/20080924donaldhawkins.aspx

‘rehabilitation potential’, and personal circumstances such as appropriate housing to be discharged to. At the time of conducting the fieldwork, the average length of stay on a stroke unit was 35 days (Smeeton *et al.* 2009)[17].

Once a patient has been discharged from the stroke unit, care is transferred to their General Practitioner (GP) and health care professionals working in the community (physiotherapists, speech and language specialists, and occupational therapists) (Smeeton *et al.* 2009). This post-discharge period of care was often described by stroke survivors I met through the course of the research as the least satisfactory. They described their experience of services as disjointed and they felt abandoned, with little or no support or information once they had been discharged from hospital. A need to develop long-term stroke care was identified in Department of Health (DoH) policy recommendations and clinical guidelines (Department of Health 2007;National Audit Office 2010;NHS Improvement 2010; Intercollegiate Stroke Working Party 2008). The discrepancy in quality between the acute hospital phase of care and post-hospital or longer term care is reflected in research. Acute stroke care has been well researched, but there is a considerable research gap on what happens to people when they leave hospital and in the years following their stroke, and how services are meeting these needs (McKevitt *et al.* 2011).

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[17] This figure is now falling due to new service design and pressure on health care professionals to reduce length of stay.

The isolating effects of stroke

Early on in the study, as I was gradually getting to meet local stroke survivors, conversations would often involve discussions on the problems of neighbourhood change and the perceived lack of community spirit. People described feelings of isolation due to the geographical separation of families, the ageing process, health events such as a stroke, and neighbours not knowing one another anymore. During a coffee break at a get-together to promote stroke survivors' involvement in improving stroke services, Pam, a woman in her 60s who cared for her disabled son and her husband who had survived a stroke, fired up with ideas of what could be done to improve living conditions for the local community, suggested that the government ought to support older people to employ their younger neighbours to help them out around the home. That way 'young mums could earn a living' and a community would develop as 'neighbours would begin to get to know one another and could then look out for each other'.

Olive, who was in her 80s and had had a series of strokes, attended the stroke get-together and talked to me about the isolating effects of stroke, worsened by the changing patterns of family life:

> Olive: Well everybody ain't stupid, but there is some people who are a bit slow and having a stroke makes you slower. You lose some of your senses at the time but yeah I think the general public should mix with people who've had a stroke. You know, when I came back in the car from that [stroke get-together] with a woman and I've made friends with her since. She lives on this estate at the back here and I found out she gets nobody to visit her and all she gets once a week is her daughter who lives in Kent somewhere – she's at work and has got kids. She come up on a Saturday, cleans the house for her, the flat for her and does all the shopping for the week you know and that's the only person, apart from a neighbour that might say 'hello', that sees her. So I go round there a couple of times a week. [Laughing] I go next door, sit and listen to all

> the moans like you're sitting and listening to me and we made friends like. … Dorothy's her first name but I can't think of her last name. But as I say I go around: I phone her up and say 'Can I come around?' and 'Ooh yes come round' and we have a good laugh and I get her fruit and stuff from down the market if I can see what she's got on the dish. …but as I say a lot of them are left on their own. A lot of families can't be bothered with them you know. … but no I definitely think a lot of people as I say who have had strokes if they haven't got any very close or near family they're a bit neglected like you know. … I wish there was some sort of clubs – like a social club say twice a week. But then again they'd have to have transport and that's what costs money.
>
> Interview with Olive, 10th August 2005

Others described isolation in terms of restrictions on their movement. Arthur, a quiet man in his 70s, told me that his participation in the project was restricted because he did not like to go out after half-past three in the afternoon as he did not feel safe. The consequences of stroke further increased isolation. Mr and Mrs James were virtually imprisoned in their flat on the 13th floor of a high rise block of flats. The unreliable lifts meant they were reluctant to risk a journey out in case the lifts were not working on their return, which would mean Mr James, who was in a wheelchair after his stroke, would be unable to get back up to the 13th floor and into the flat.

Reduced confidence, relocation to more appropriate housing, reduced mobility, all associated with surviving a stroke, resulted in some survivors withdrawing from their existing networks and isolated them from others in a similar situation. During fieldwork, it was common to hear stroke survivors remark that their involvement in either of the two enterprises was the first time that they had met another stroke survivor.

With the exception of a couple of organisations, stroke survivors have not had a visible presence in Lambeth and Southwark. For example, the chief executive of a disability charity in Lambeth commented, during a meeting to establish a network of stroke survivors, that people with stroke had been ‘non-existent’ in the organisation. This is despite stroke being the leading cause of adult disability in the UK. Research by Moss *et al.* (2004) investigating how identities of people with aphasia are represented in aphasia, stroke and disability websites found that disability-related organisations excluded those with aphasia either through poor communication or because aphasia was not included in the category ‘disabled’.

Some efforts, nationally as well as locally, have been made to reduce isolation of stroke survivors. The Stroke Association, through an affiliation scheme, promotes and supports stroke clubs in the local community; groups for stroke survivors and their relatives or those who care for them. Stroke clubs, self-financing and run by volunteers, aim to provide a regular meeting place for people to come together and share their experiences and opportunities to take part in a programme of activities such as speakers, exercise classes and lunches (The Stroke Association 2011).

In Lambeth and Southwark, a handful of community based organisations provide support to stroke survivors. A local charity with roots in Bermondsey runs the only stroke club in the two boroughs. The club has membership of about 20 people from the Rotherhithe and Bermondsey areas of Southwark and provides a limited minibus service to take members to and from meetings. However, the club is constantly struggling for resources to enable more stroke survivors to attend.

Another voluntary sector organisation in the local community, Connect, supports the needs of stroke survivors, focusing in particular on the needs of people with aphasia. They provide counselling, classes and support groups for people with aphasia and training for researchers and health care professionals who work with people with aphasia. The organisation's philosophy is that directly experiencing aphasia engenders expertise in aphasia. Members are encouraged to view themselves as experts in the same way as one may view a health care professional as an expert. This philosophy of expertise extends to the organisational structure. Those with aphasia are involved in shaping and influencing the organisation. They advise and participate in the delivery of new services, training courses and publications, advise the organisation and act as the organisation's trustees. This organisation had a considerable role in involving local stroke survivors in the project to modernise stroke services. Policy calls for modernisation of stroke services was a significant theme both locally and nationally for the duration of this research, as I discuss below.

5.2. The policy context

The research undertaken was conducted with policy initiatives operating at both national and local levels to 'modernise' health services in general and, more specifically, stroke services. The period of fieldwork coincided with an intensification of policy at the national level to improve stroke services. In 2005, the National Audit

Office (NAO) published a highly critical report of the state of stroke services in England and Wales (National Audit Office 2005). The report identified that progress in the efficiency and effectiveness of treatment provided to stroke patients was not as good as it could be, with delays in treatment increasing the risk of death and disability; that patients and carers were left feeling abandoned after discharge from hospital due to a lack of integrated health and social care services and a scarcity of health professionals within the community care sector; and that the general public's awareness of stroke was low, putting in jeopardy the emergency response stroke requires. In 2007, the government published their response to the NAO report – the Stroke Strategy (Department of Health 2007).

The NHS Modernisation Agency was established in 2001 as an arm's-length body within the DoH to support ministers implementing the NHS Plan to make health services more efficient, effective and responsive to patients' needs (Department of Health 2003;Greenhalgh *et al.* 2009). As with other DoH initiatives, user involvement and the need for it to be incorporated into all aspects of service redesign was stressed. In 2004, the Modernisation Agency was abolished as it was deemed not to be providing value for money. However, before this, whilst 'modernisation' was still on the DoH's agenda, a large-scale project of health service modernisation was established in Lambeth and Southwark which formed one of my research sites, which I detail below.

5.3. The Transforming Stroke Services Project

Following concerns identified by local people, clinicians and academics that the quality of NHS care in this deprived, inner city part of London needed improving, a hospital charity identified three disease areas in line for modernisation. In 2003, the Guys and St Thomas' Charity allocated £15 million to health care providers in Lambeth and Southwark for a 'Transformation Project' to modernise health services in stroke, kidney disease, and sexual health (Greenhalgh *et al.* 2009).

The original application, citing the need for stroke service modernisation, was devised by a small team of local stroke clinicians, researchers and voluntary sector leads, with input from local stroke survivors via a consultation activity on their view of how stroke services and care in the two boroughs needed to change. Despite the two boroughs housing one of the early adopters of the stroke unit model of care, St Thomas' Hospital, there were concerns about the quality of stroke care. For example, people who had had a stroke were not always admitted to the stroke unit because of insufficient capacity and a lack of knowledge on the part of emergency staff to admit stroke patients to the stroke unit. Rehabilitation services were unable to keep up with demand, and community services were not stroke specific and largely uncoordinated. Historically, low levels of health care professionals with specialist stroke knowledge have made delivering stroke services more difficult[18]. As described earlier in this chapter, services in the period after discharge from hospital were disjointed and in the long term little support, apart from that provided by one or two local voluntary organisations, was available for stroke survivors to learn to cope with their disability. This latter aspect was not seen as something relevant to, or requiring, professional input (National Audit Office 2010). The problems identified with stroke services in Lambeth and Southwark were not unique to this part of London. Similar concerns with stroke services were prevalent across England and Wales, as discussed earlier in this chapter, through the publication of the NAO's critical report on stroke services (NAO 2005).

The Transforming Stroke Service Project (TSSP) commenced in 2004, with an ambitious remit to transform hospital and community services into an 'integrated and co-ordinated care pathway' ensuring early access to diagnosis and treatment; provide services that meet the practical and emotional needs of people adapting to life after stroke; modernise working practices; and provide information and education for those effected by stroke and for staff. The vision of the TSSP was that:

> fewer people should have strokes in Lambeth and Southwark and that people who do have a stroke and their carers should achieve the quality of life they seek through receiving the services they need at the point that they need them, from the start of stroke symptoms and for the rest of their lives.
>
> TSSP proposal (n.d.)

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[18] As momentum to improve stroke services nationally has grown, stroke is now seen as a clinical specialism, rather than an area of general or geriatric medicine (McKevitt *et al.* 2010b).

Access to the TSSP was easily negotiated since research findings from the Stroke Research Programme had been key to establishing the need for the TSSP. Senior members of the SRP were involved in overseeing the TSSP. Prior to my employment, the Principal Investigator (PI) had approached those responsible for user involvement in the project to suggest that King's College London researchers could evaluate user involvement in the TSSP. Since it had been explained that I would be conducting participant observation and would be available to help out with user involvement-related tasks this helped negotiate access to the setting. Furthermore, professionals on the TSSP were interested in the research questions of my thesis and the wider research project – particularly the factors which facilitate or hinder stroke survivor involvement. This further helped me to gain access to the setting as I was seen as providing useful information to TSSP professionals. Shuttleworth (2004) describes a similar experience that helped him gain access to a research setting. Shuttleworth's research participants – young, disabled men – were keen for someone to research disability and sexuality issues, granting easier access for Shuttleworth to the setting and participants, even though he was criticised by some from the disability community for undertaking such research as a non-disabled researcher (Shuttleworth 2004).

The TSSP was organised into four workstreams, overseen by a Project Management Group (see Figure 5.2, overleaf). The TSSP was managed by Debbie, a nurse by training who had taken the NHS management career path. Debbie, in turn, reported to Karen, the Transformation Project Director, who had overall responsibility for all three transformation projects (stroke, kidney disease and sexual health). In addition to administrative staff, the TSSP employed eight ‘Service Improvement Facilitators’, lower grade NHS managers, who were responsible for planning and implementing improvements to stroke services, each taking responsibility for an aspect of patient care within one of the four workstreams. Stroke clinicians, health care professionals (nurses, physiotherapists, and speech and language therapists) and professionals from the voluntary sector worked on the project. The project covered the costs of releasing these professionals from their day jobs so that they could be involved in the project.

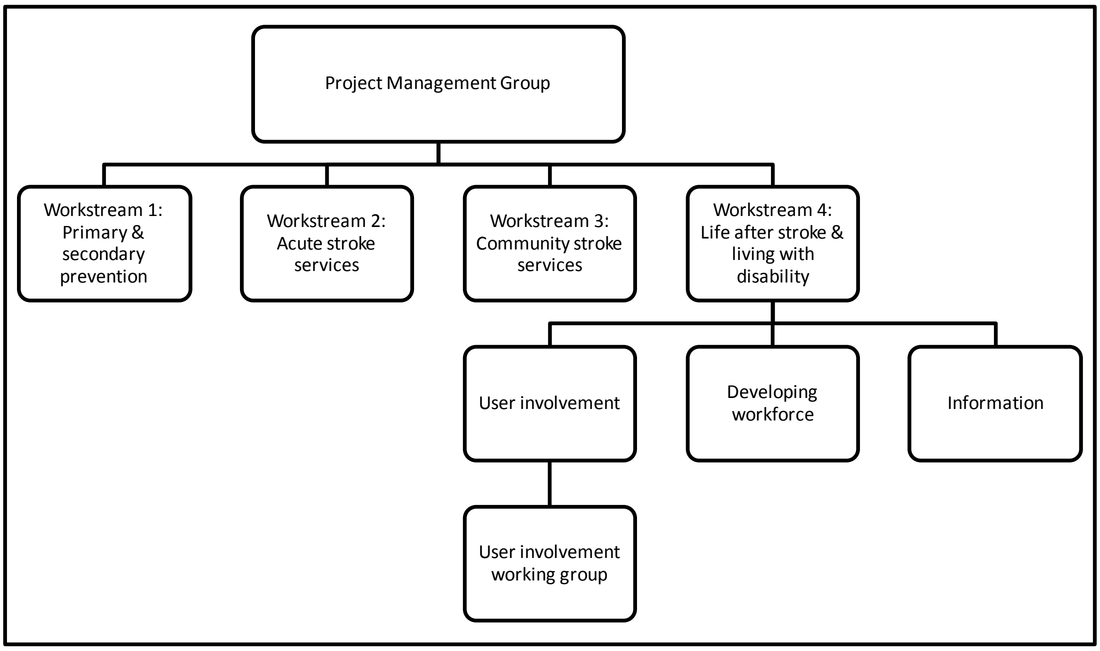

Figure 5.2 Structure of the Transforming Stroke Services Project

The first three workstreams focused on stroke services, from stroke prevention (workstream 1) to the acute services a patient receives in hospital when they first have their stroke (workstream 2), through to the services stroke patients receive in the community once discharged from hospital (workstream 3). The fourth workstream focused on user involvement, workforce development and information. It was intended as an 'infrastructure workstream' to support the other three workstreams. Jackie, a service improvement facilitator whom I worked with most closely during participant observation, was employed to lead workstream 4. Within the workstream, Jackie's main responsibility was to implement user involvement throughout the TSSP.

Jackie's professional background was social work. Through this she had gained experience of involving service users in service development particularly in the field of HIV and AIDS. Jackie recounted and contrasted her previous experience working with people living with HIV/AIDS to that of stroke survivors. Jackie commented that there had been considerable political involvement from people living with HIV and AIDS to participate in service development, coupled with a commitment to user involvement from professionals who chose to work in that field. This prior exposure to different models of patient and healthcare provider relationships made Jackie aware of the power differentials between patients and providers. Jackie would often use the adjective 'powerful' to describe user involvement-related activities which appeared to be emotionally effective in raising the profile of patients as experts in their own health. Jackie and I developed a close relationship and camaraderie through our attempts to establish user involvement and the obstacles and challenges that we were frequently presented with.

The TSSP was housed in a small part of an old, rambling and somewhat derelict hospital site near Elephant and Castle. To enter the building, I would press a bell on an intercom by the main door and once it was answered, announce who I was and who I was here to see. I would then be buzzed in and I would make my way along a large empty corridor towards the TSSP offices. The offices were on the first floor of the former hospital, accessed via a flight of stairs. Although the building had a lift, a sign indicated that it was not to be used. The offices were located off a central corridor and consisted of one large open plan office, where most of the NHS managers and clinicians seconded to the TSSP worked, and a couple of smaller open plan offices for TSSP director, computing and administrative staff, meeting rooms, and kitchen and toilet facilities. Most people had their own desk, but some TSSP staff such as doctors, therapists, and nurses who had been seconded to the project for one day a week used hot desks. When I worked at the TSSP offices, I would try to find myself a hot desk near Jackie so that I could catch up with user involvement developments whilst getting on with the necessary tasks.

The TSSP, therefore, was an enterprise, located within a wider programme of service modernisation, to improve and develop stroke services in Lambeth and Southwark. The vision of the TSSP was to reduce the number of people having a stroke in Lambeth and Southwark and to provide integrated services to deal with treatment, rehabilitation and living with the effects of stroke. The TSSP aimed to achieve this vision through close collaboration with people who have had a stroke. The other enterprise, within which I conducted participant observation, the Stroke Research Programme, was concerned with stroke prevalence and incidence in the two boroughs as well as the quality of stroke services provided locally from the perspective of conducting research. However, the driver for stroke survivor participation in this context differed, as I illustrate in the following section.

5.4. The Stroke Research Programme

The Stroke Research Programme (SRP) forms a discrete research programme within a wider academic department of public health in the School of Medicine at King’s College London (KCL). KCL undertakes research in a variety of areas, but health and medicine is one of its strongest research domains, generating an income of nearly £350 million in research grants (King's College London 2005). Over the years, the college has grown through a series of mergers with medical and dental colleges: King’s College Hospital Medical School, the Institute of Psychiatry and the United Medical and Dental Schools of Guy’s and St Thomas’ Hospitals. KCL is now affiliated with three local NHS Foundation Trusts to form an Academic Health Sciences Centre. In terms of its relationship with the local community the university is probably better known through its association with the three teaching hospitals: Guy’s, St Thomas’ and King’s. In its commitment to ‘participation’, the college runs an access scheme to encourage and enable local school students to study at medical school or train for careers in the health service or biomedical sciences.

Over the course of my observations, there were 31 researchers employed in the SRP although on average about 20 researchers were employed at any one time. The team included fieldworkers, doctors, health economists, social scientists, epidemiologists, statisticians and data managers/analysts. The SRP is overseen by Professor Brooks, with managerial input from three to four senior researcher staff who are the principal investigators on research grants within the SRP. The remainder of the team consists of junior clinical and non-clinical researchers, some undertaking doctoral research. The SRP undertakes a range of research studies investigating epidemiology and natural history of stroke, stroke outcomes, access to and evaluation of services, stroke prevention, and patients' experiences of and perspectives on stroke and stroke services, funded by research grants from medical charities, Research Councils and the DoH. Central to much of the research conducted by the team is the South London Stroke Register, known as the SLSR, or more informally by both stroke patients and researchers as ‘The Register’.

Established in 1995 to investigate ethnic differences in stroke, the SLSR is a register of all people who have had a stroke in a defined area of Lambeth and Southwark. As an epidemiological study, the SLSR seeks to answer questions about population health as opposed to the health of individuals. Register participants are identified, through multiple notification sources, to be included on the register at the time of their stroke (Stewart *et al.* 1999). By the end of 2007, 4066 participants had been registered, 1798 of whom had survived their stroke. Participants are followed up by a fieldworker administering a questionnaire at the time of the stroke, three months, and then yearly after their stroke. The questionnaire can take up to an hour for a fieldworker or researcher to complete with the Register participant and covers topics such as use of health and social care services and level of disability post-stroke. A series of generic and stroke-specific standardised health measures are included in the questionnaire to ascertain physical functioning, well-being, physical and mental health, and perception of health. What may be construed by Register participants as 'medical procedures' are conducted through the course of the collecting data such as recording participants' blood pressure and asking questions about medication, smoking behaviour and alcohol consumption.

The SRP is housed on one floor of a rented, nine-storey office block near Guy's Hospital. The building is home to various research groups and central, administrative university departments such as Estates and Human Resources. The building was refurbished over the summer of 2005 to improve the decoration. In compliance with disability access laws (Disability Discrimination Act 2005), handrails, often mistaken by building inhabitants as toilet roll holders, were fitted into the toilets to enable use by those with disabilities. However, someone who is in a wheelchair cannot use the toilets as the cubicles have not been fully adapted to allow access for a wheelchair, let alone give someone the space required to transfer from the wheelchair to the toilet. Furthermore, the lifts cannot accommodate a wheelchair, making access to the meeting rooms and offices impossible for a wheelchair user. I contacted Estates during the refurbishment to ask them why fully accessible disabled toilets were not being installed. Their response was that because the university does not own the building they were reluctant to spend money on expensive adaptations, and given that the building tends not to be used by students or the general public, it was felt that there was little need to make it fully accessible. The reluctance of the organisation to make the building fully accessible had implications for the PI and I when we came to establish user involvement and invite stroke survivors to participate in the research programme as I shall discuss in Chapter 7.

Prior to my employment, researchers in the SRP had made an attempt to involve Register participants in research the programme undertook. In 2000, prompted by the emerging polices and research governance requirements to involve consumers[19] in research, two meetings were organised by SRP researchers to involve SLSR participants in the work of the Register. Seventeen SLSR participants attended the first meeting where research priorities for stroke and how research should be conducted were discussed with researchers. A second meeting was held, but was only attended by two Register participants. Due to lack of resources, including staff time which could be dedicated to establishing consumer involvement, no further meetings were held.

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[19] In the mid-1990s patients and the public were referred to as 'consumers'. In 1996 'Consumers in NHS Research' was established by Research and Development Committee of the Department of Health to promote consumer involvement in research. 'Consumers in NHS Research' changed its name to 'Involve' in 2003 (http://www.invo.org.uk/History.asp). The term 'consumer' implies that the health care system is a market place. The preferred terms now are ones that I am using throughout this thesis: 'patients and the public', 'service users', 'survivors'.

However, as the policy gained momentum and prominence in research governance and funding requirements, the Head of the SRP told me during an interview, that he saw the policy of user involvement as an entrepreneurial opportunity to research the phenomenon and produce high quality publications on the topic. He believed that the added benefit of establishing user involvement in the SRP through the research endeavour would mean that policy and research governance requirements to involve patients could be met and would be ‘one less thing to worry about.’ In 2004 a senior researcher (the PI) submitted a research proposal on the topic for funding, which included an opportunity for a research associate to undertake doctoral research on the phenomenon of user involvement. Towards the end of 2004, the research proposal was awarded funding and I was employed as a researcher to establish and evaluate the involvement of stroke survivors as a form of participation.

As an employee and member of the SRP, access to meetings where stroke research and the Register were discussed was easily negotiated since my participation in these meetings was often a requirement of my employment. The fieldworkers, doctors and nurses working directly on the Register attended a fortnightly meeting to discuss issues related to management of the Register. During the first couple of months of data collection, I attended these Register meetings as I thought the meeting might provide some useful insights into user involvement. However, after five meetings I stopped attending as the involvement of stroke survivors in the Register never arose as a topic of discussion. The meetings mainly focussed on procedural matters concerning the running of the Register, such as ensuring that notifications of new stroke cases had been properly recorded and that follow up appointments with Register participants had been completed. This suggests that the policy to involve participants as partners in research had little relevance or bearing on those researchers whose main role was to ensure Register data were collected according to the correct operating procedures. It raises questions about who within a research team is responsible for implementing user involvement, a question I shall address later on in the thesis (see Chapter 7).

5.5. Conclusion

In this chapter, in order to situate the research, I have introduced the multi-sited aspect of this ethnography by describing the geographical location, the local community and the two enterprises where I conducted participant observation. ‘The field’ where this ethnography took place contrasts with classical anthropological notions of ‘the field’, which tend to be bounded and discrete. The ‘unbounded’ nature of the field in this research included the geographical locality as well as the policy imperative to introduce a cultural shift in the way patients and professionals interact to develop services and conduct research.

The TSSP was concerned with improving and developing stroke services in the two boroughs, with initial project documents describing the involvement of stroke patients as central to plans to improve services. The SRP was concerned with undertaking stroke research within an academic department of public health research. User involvement in this setting was driven by research governance requirements to involve patients, combined with a research opportunity to investigate the phenomenon of user involvement. Like Hansen, I too took a broad definition of ‘the field’ (Hansen 1997). I considered policy documents, media, participation in conferences, newsletters as well as observations of the actors participating in the two enterprises to think about the wider questions related to citizen engagement and citizen and expert power, within the context of health service development and health research.

Chapter 6: The enactment of user involvement policy in a health service organisation

As I described in Chapter 1, the involvement of patients and the public in decisions about the planning, design, development and delivery of local services is predicated on the assumption that this will lead to improved services and better outcomes for patients (Department of Health 1999;Department of Health 2000). Patients are not only encouraged to exercise greater control over their own health, but their involvement is encouraged in the development of health services. Department of Health (DoH) policy documents are explicit about a need to transform the relationship between patients and professionals (Department of Health 2001c;Department of Health 2005a;Department of Health 2006) arguing that a transfer of power is required from professionals to patients 'to create new working relationships between patients and frontline staff' (Department of Health 2001c: 3). The stated goal is to 'move away from a paternalistic model of decision-making, towards a model of partnership, whereby citizens have greater connection to their local services, and have a say in how they are designed, developed and delivered' (Department of Health 2001b: 27).

Central to this chapter is an examination of how this policy was enacted at the local level by the Transforming Stroke Services Project (TSSP). At an empirical level I explore how the policy of user involvement was interpreted and implemented within a health service organisation and I aim to elucidate the factors which may have influenced how user involvement was put into practice. At a theoretical level this chapter investigates:

- whether the transformation of the relationship between patients and professionals, a cited aim of user involvement policy and wider health care reforms, was achieved through implementation of user involvement; in other words was power transferred from professionals to patients?
- whether new forms of citizen were produced as a result of implementation of user involvement policy. In the context of health care reforms that encourage patients to exercise greater control over their own health care and the services they use, did implementation of user involvement practices create empowered citizens?

Through describing how user involvement was interpreted and implemented in the TSSP, I will argue that DoH policy on user involvement was reinterpreted for implementation by TSSP professionals as a duty to consult with service users. However, implementation of user involvement was not viewed as a mechanism to transform relationships between patients and professionals and transfer power to patients as indicated in the policy.

The chapter is in three parts. First, I describe ambitious plans to involve stroke survivors in the work of the TSSP, as enshrined in TSSP policy documents. These plans were based on a reinterpretation of DoH policy on user involvement. However, TSSP plans were not as explicit as DoH policy in their aim to transform relationships between patients and professionals. I then describe how a team of TSSP professionals enacted user involvement based on this reinterpretation of the policy. Second, I turn to user involvement practices in the TSSP. I describe the user involvement activities practised and focus on professionals' views of involvement. I argue that user involvement practices were shaped by the professionalised nature of user involvement within the TSSP. Third, I turn to stroke survivors' views of user involvement policy, what they thought of the TSSP and their role within the project. I argue that stroke survivors' experience and interpretation of involvement further impeded a transformation of patient and professional roles.

6.1. Formulating and enacting an ethos of user involvement

From the outset of fieldwork I began collecting and analysing documents such as the TSSP proposal and newsletters because these documents revealed the vision of user involvement publicly promoted. A small team of stroke clinicians, researchers and voluntary sector leads had written the TSSP proposal which had granted them funding. Although the policy of user involvement was enshrined in just a few lines within the proposal, plans to involve stroke survivors were ambitious. It was stated that the stroke service improvement would be achieved through:

> close collaborative working with people who have had stroke in designing and delivering integrated services to support all stages of treatment, rehabilitation and learning to live with stroke.
>
> TSSP proposal (n.d.)

Whilst these documents reveal the importance granted to user within the TSSP, the documents were unclear regarding the extent of control and influence stroke survivors would have over the project, with some documents indicating that stroke survivors would have control whilst others simply stated stroke survivors would be ‘involved’. For example, adopting similar rhetoric to that in DoH policy documents, the first issue of a newsletter aimed at informing and updating stroke survivors about the TSSP and its progress, contained an article promoting user involvement in the project announced that people with stroke would be ‘in the driving seat’. This metaphor, although used rhetorically, seemed particularly insensitive and ill-chosen given that in many cases of stroke, one of the first freedoms a stroke survivor loses is permission to drive, due to the significant potential risks associated with driving after stroke (Intercollegiate Stroke Working Party 2008). The newsletter article continued, stating that the TSSP would:

> Recruit and train people with stroke and their carers to get involved in our working groups, and make sure [the TSSP] is delivering what our local residents need and want
>
> TSSP Newsletter Issue 1 September 2004

A subsequent newsletter further reiterated the ethos of involvement and the TSSP’s commitment to user involvement:

> people who have had strokes and their carers [will be] fully involved in every aspect of the work to improve services across Lambeth and Southwark.
>
> TSSP Newsletter Issue 2 January 2005

The interpretation of user involvement policy at the level of the TSSP proposal document and newsletters was influenced by DoH rhetoric and made reference to collaborative working between patients and professionals. However, unlike DoH policy documents, TSSP documents did not explicitly suggest that the implementation of user involvement within the TSSP would require, or result in, a transfer of power from professionals to patients, or that ‘involvement’ was concerned with empowering stroke survivors. Rather, the necessity to involve stroke survivors within the TSSP can be seen to reflect the legal duty for NHS professionals to involve and consult with patients, carers and the public, as set out in the Health and Social Care Act of 2001 and subsequent NHS Acts (Health and Social Care Act 2001; National Health Service Act 2006; Local Government and Public Involvement in Health Act 2007).

As with DoH policy documents, there were no specific documents or plans within the TSSP detailing how collaborative working between professionals and patients was to be achieved, nor what it might look like in practice. Responsibility for implementing user involvement on the ground rested largely with Jackie, the service improvement facilitator assigned to implement user involvement throughout the TSSP, who I introduced in Chapter 5. Understanding what ‘user involvement’ looked like in practice was my task in the field. In the following sections I describe the steps taken by Jackie, her colleagues and me to implement user involvement policy.

Planning how to ‘do user involvement’

In December 2004, my first introduction to the TSSP and ‘user involvement’ was a meeting of the User Involvement Working Group (UIWG) – a group established to develop and implement a strategy for involvement in the TSSP. When I arrived at the meeting Jackie, who chaired the UIWG and Sarah[20] were setting up the room – arranging a flip chart and putting glasses, bottles of water, fruit and chocolate biscuits on the table. Gradually other members of the working group began to arrive and Jackie suggested that we start the meeting.

The UIWG had met once prior to my beginning fieldwork. Membership of the group constituted Jackie from the TSSP, three people from local stroke-related charities, two public involvement managers from local Primary Care Trusts, a member of the Expert Patients Programme[21], a community physiotherapist and a clinical nurse specialist from a local stroke unit. The PI and I were considered members of the group since the PI had conceived the research project to investigate user involvement, and through participant observation I would be working closely with Jackie to help implement user involvement.

Jackie passed around the meeting agenda and a number of supporting documents – ‘terms of reference’ and ‘job descriptions’ for the group and its members. Jackie asked us to let her know of any changes we thought needed to be made to these documents before the next meeting so they could be approved. Jackie emphasised that the main task for the meeting was to establish how best to identify people living with stroke in

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[20] Sarah was an administrator for the TSSP who later became responsible for developing stroke information provision working closely with stroke survivors.

[21] The Expert Patient Programme is a core element of chronic disease management in the UK. Trainers with experience of a chronic disease train other patients with a range of chronic diseases in a range of generic skills to help them to self-manage their condition (Rogers *et al.* 2008).

the local area so that they could be invited to a ‘stroke get-together’ where they could find out about the TSSP and how they could be involved in it. However, a number of tensions seemed to be holding back decision-making about how to proceed with development of plans to implement user involvement. The fact that there were no stroke survivors in the UIWG was a particular problem for Jackie and Mary, an employee of a communication disability charity which had a strong ethos of involving people who used the charity in decision-making and running of services. Both women felt that the involvement of stroke survivors within the TSSP could only go so far until stroke survivors were actually on board to determine the direction the project should be going in. Mary felt that the TSSP needed more time to clarify why and how people with stroke were being involved in the project, suggesting that the TSSP proposal did not provide this clarity. One of the PCT PPI managers interrupted this discussion and curtly said that the group ‘cannot have these discussions as an excuse for not having [service] users on board yet. At some point soon you have to take the plunge and get users on board’.

The UIWG continued to meet regularly over the three years of the TSSP; every other week while stroke survivors were being sought and encouraged to participate in the TSSP, then monthly once stroke survivors had been invited to and attended the stroke get-together. Despite the initial enthusiasm for user involvement, membership of the group quickly tailed off. After the group had meet for a second time, only six of the original 12 members regularly attended meetings: Jackie; Mary; Sharon, the community physiotherapist; Margaret, the clinical nurse specialist; and the PI and me.

During meetings Jackie reported that absent members had told her that they were too busy to attend meetings. Jackie, in a resigned tone, reflected that ‘user involvement was yet another task’ those working within the NHS are charged with.

The UIWG meetings were held either in a meeting room at the TSSP offices or at the headquarters of a local stroke charity who were involved in the TSSP. Meetings initially followed the formal structure of a business meeting with meeting dates scheduled into diaries, and meeting agenda and minutes sent out by email. However, during the meetings themselves the usual formal practices of a meeting tended to be less strictly adhered to. For example, whilst Jackie, the PI and I would always arrive for meetings on time, other group members would arrive late, often 30 minutes to one hour after the agreed start time. Discussing the official business of the meeting would therefore be delayed or the order of the agenda would be changed while we waited for a particular member to arrive who needed to be present to enable a full discussion of an agenda item.

In the first few months of the life of the UIWG, meetings would last for about two hours, often running over the planned finish time. The meetings had a reflective, confessional air about them, as members grappled with visualising what user involvement would look like within the TSSP, and tried to think about how the ethos of user involvement as set out in TSSP documents might be implemented. For example, Jackie used these meetings to air some of the concerns she had with implementing user involvement across the TSSP. Jackie frequently voiced her concerns during UIWG meetings that the TSSP would not be able to persuade stroke survivors to be involved as the policy demanded: ‘Would any service users be interested in the TSSP’; ‘how do we find and recruit service users to the project’; and ‘how do we encourage sceptical colleagues to engage with stroke survivors’.

By the time the UIWG had met for a third time, it became apparent to me that less ambitious plans for involving stroke survivors were being made. Margaret, the clinical nurse specialist, asked, ‘Are we looking for user involvement on *every* workstream?’ ‘That is what is certainly planned’ said Jackie, although Mary (the employee of a communication disability charity) added that she thought that ‘we’re probably not going to get a lot of people interested in becoming involved’ and wondered whether it was actually ‘realistic to get users involved in *all* the workstreams’.

That user involvement would be less ambitious was made clear in a subsequent meeting when Mary confirmed that ‘although we had initially said a stroke [service] user should be in each workstream and on the TSSP Management Group’ she thought these aims were too difficult to achieve. Instead she thought ‘the target should be to get users [involved in] the user involvement workstream [workstream four]’. She argued that later, through a ‘filtering approach’, service users could be involved in the other workstreams[22]. Jackie agreed and said that currently, workstream one (stroke prevention) ‘was too technical and would be difficult for users to get involved’, but once the workstream started to work on services and interventions to prevent stroke

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[22] See chapter 5, section 5.3 for a diagram illustrating the workstream structure of the TSSP.

in the community then service users could be involved. During some of the first few UIWG meetings Mary would often report her fears of introducing stroke survivors into the PMG. Mary was the only member of the UIWG who had direct experience of the PMG, having been one of the original founders of the TSSP. Mary revealed that she envisaged difficulties with the TSSP Management Group. She said she found it hard herself to ‘keep up with all the NHS terminology’ used in the meetings and did not know how ‘users would be able to keep up’. Both Jackie and Mary agreed that ‘politically there would have to be users in the TSSP Management Group’ but neither was sure how good an idea it was, as they did not think the group was ready to ‘accept [service] users’.

Thus, through the practices of implementing user involvement, the ambitious aims for stroke survivor involvement, as set out in TSSP proposals and newsletters, were watered down to aims thought to be more realistic and achievable. The suggestion, by Mary, that the TSSP Management Group was not ready to accept service users is indicative of how difficult it is to achieve the wider policy aims for partnership working and transformation of patient and professional roles.

Locating stroke survivors

DoH policy on user involvement is silent about how patients and professionals will be brought together, assuming that a community of patients to involve in service development readily exists. However, this was not the case with implementing stroke survivor involvement in Lambeth and Southwark. Implementing user involvement in the TSSP required considerable efforts to seek out stroke survivors via community and voluntary organisations, explain the TSSP to them and why their input was needed, and encourage and persuade them to attend a ‘stroke get-together’ where they would be able to find out more about the project and ‘ways to become involved’.

In Chapter 5, I described how stroke patients, once discharged from hospital, are looked after by their General Practitioner (GP). If further rehabilitation is required they will be treated for a limited time by community-based physiotherapists, speech and language specialists, or occupational therapists. Since stroke patients do not receive follow up care via an outpatient’s clinic, as is the case for patients with other long term medical conditions such as diabetes or kidney disease, Jackie and I did not have a readily available avenue through which to identify and invite stroke survivors to participate in the TSSP. The lack of community organisations in the two boroughs specifically aimed at stroke survivors[23] further hampered our ability to find stroke survivors and carers to invite to the planned stroke get-together.

Jackie’s strategy was to contact voluntary and community groups operating within the two boroughs, some of whose members may have had a stroke. Jackie and I contacted 33 such groups, ranging from large, formal organisations such as the Stroke Association to smaller, informal groups such as a local ‘Over 60s Club’. Some community organisations focussed on certain population groups, where membership was defined

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[25] In Chapter 5, I stated that there were only two community organisations in the two boroughs which specifically catered for the needs of stroke survivors - a communication disability charity and a stroke club (see Chapter 5, section 5.1 ‘The isolating effects of stroke’ for further details on these two organisations)

by ethnicity or religious affiliation, health status (i.e. the two local stroke specific groups referred to previously) and caring status (i.e. organisations whose members were the informal and unpaid carers of people with ill health or a disability).If the club organiser agreed that the get-together would be relevant to their members we sent them a bundle of invitations to be handed out on behalf of the TSSP.

The Stroke Research Programme had agreed to help the TSSP recruit stroke survivors by sending an invitation to the get-together to everyone on the South London Stroke Register (SLSR). Stroke clinicians linked to the TSSP handed out invitations to stroke patients they were seeing either in hospital or in the community.

In the end, over a two month period, about 500 invitations were distributed to stroke survivors using a mixture of consecutive and convenience sampling through voluntary and community groups, a population stroke register, and hospital and community clinicians. The invitations asked stroke survivors to return a reply slip to confirm their attendance at the get-together, stated that transport would be provided for those with reduced mobility as a result of stroke or other conditions and that lunch would be provided. Once invitations had been sent out and people had begun to return their reply slips, we telephoned those stroke survivors who had agreed to attend the event to arrange taxis or ambulances for those with mobility problems or to organise carers for those needing assistance with personal care. A considerable amount of ground work was also undertaken speaking to stroke survivors who had returned the reply slip but who were not entirely sure about attending the get-together, as it was not clear to them what the TSSP was or what their participation in the project would entail.

Much to Jackie's surprise and relief more stroke survivors than anticipated wished to attend the get-together. To accommodate all those who wanted to come, two 'get-togethers' were held on different days with about 30 stroke survivors attending each meeting. Both meetings were run along a similar format. Below, I describe the first get-together I attended.

The stroke get-together

It was ten o'clock on a mid-March morning and stroke survivors began to gather in the café area of the headquarters of a stroke charity for the stroke get-together. I, along with a few other helpers from the TSSP, took people's coats, made teas and coffees, and sat down to chat to those who had arrived while we waited for the stroke get-together to start. Ruby was the first person I spoke to. She was of Indian origin, 79 years of age, having had her stroke over five years ago. Ruby lived in sheltered accommodation and twice a week attended a day centre, which is how she had heard about the stroke get-together. Jackie had visited the day centre one day and given a talk about stroke services and Ruby thought it would be interesting to come along to 'know what's happened, what's going on'. Next to arrive and sit down with Ruby and me were Mr and Mrs Todd, a white, retired couple both in their late 60s who had lived in the area for most of their lives. Mr Todd had had a stroke and had heard about the get-together through the SLSR. He asked me if there would be a doctor at the get-together and was somewhat disappointed when I said that there would not be.

I then spoke to Irene and Cynthia, white women aged 83 and 74 respectively, who were, or had been in the case of Irene, informal carers to people who had had a stroke.

Irene’s husband had a stroke and she looked after him until his death, as well as running a pensioners’ club. Irene talked about attending the get-together as a way of ‘giving something back’. Since her husband’s death Irene felt she was finally in a position to share the experience and knowledge she had acquired through caring for her husband in the hope that it could help others. Cynthia described herself as a carer to her friend who had had a stroke. She said that her reason for attending the get-together was to see what additional services she could get for her friend.

Once those attending the get-together had been registered everyone moved upstairs to a large meeting room where the TSSP and ways stroke survivors could be involved in it were explained. Debbie, the TSSP manager, opened the get-together formally and began to tell the audience about the project, the need to listen to the views of service users and how central service user involvement was to the success of the project. Members of the audience nodded in agreement as one woman called out: ‘If you let the NHS decide you won’t get the right answers. If you speak to users you will get the right answers. Doctors must form services based on what people need.’

Members of the audience were then encouraged to recount their experiences of stroke and the services they had received and to identify problems with stroke services which needed addressing (see Figure 6.1, overleaf). These problems were recorded on a flip chart: transport; isolation, community change, housing, negative prognosis from doctors (‘You’ll never walk again’), lack of support once discharged from hospital, lack of physiotherapy, and lack of information about stroke. Debbie and the other TSSP professionals acknowledged these problems but announced that two of the problems

– transport and physiotherapy – were beyond the remit of the project. Instead, TSSP staff encouraged stroke survivors to participate in the project by joining a ‘user group’ focused on an area of service development from a pre-defined list: training healthcare professionals, developing stroke information, providing peer support, ensuring stroke survivors were involved in the project, and membership of the TSSP Management Group. After lunch, Jackie gave a quick synopsis of the five different user groups with the intention that stroke survivors would ‘sign up’ to join one or more of these user groups before they left the get-together and returned home.

Figure 6.1 Stroke survivors discuss their experiences of stroke during the stroke get-together

The stroke ‘get-together’ therefore, represents the first time in the two boroughs that stroke survivors and NHS professionals were brought together, in a new capacity, to discuss stroke services and the improvements that needed to be made to them. Whilst concerns and grievances raised by stroke survivors at the ‘get-together’ such as the lack of physiotherapy and poor transport were recognised and acknowledged by TSSP professionals as important and legitimate, these concerns were not on the TSSP’s agenda of service improvement and were consequently excluded as areas of service improvement through which stroke survivors could be involved. The areas of service improvement which were available for service user involvement had been identified by TSSP professionals prior to the stroke get-together. The two-dimensional view of power suggests that the setting of agendas or defining the terms of debate is used to constrain and channel participation (Culley & Hughey 2008). In the TSSP, the areas of service improvement in which stroke survivors could participate were determined and directed by professionals. Predefining the areas where service user involvement would be implemented further suggests that TSSP professionals were less interested in collaboration with stroke survivors or transferring power or control to stroke survivors. Instead, they were more concerned with meeting the organisational aims of the TSSP, structured according to four workstreams. User involvement activities had to fit into this pre-defined structure.

Encouraging stroke survivor involvement

Few stroke survivors attending the get-togethers chose to sign up to join the user groups Although I am not entirely sure of the reasons for this, after Jackie and I had spoken to a number of stroke survivors who had attended the event, it seemed that people were not entirely sure what joining one of these groups would entail. They were unsure of the commitment required in terms of time and what they would actually be expected to do. So, a week after the get-togethers had taken place, Jackie and I telephoned those who had attended to encourage them to join one of the user groups and to invite them to a ‘taster’ session where they would find out more about what membership of a user group would entail.

In principle, involvement in the TSSP was open to all people with stroke and their informal carers, relatives and friends. However, certain categories of stroke survivor were encouraged to become members of particular user groups based on their ethnicity, severity of post stroke disability, and level of ability to function and contribute to the different user involvement activities open to stroke survivors. This was particularly the case with recruiting stroke survivors to the TSSP Management Group.

Mary had often said in the UIWG that she fell that the TSSP Management Group was difficult to penetrate and understand, even for someone as experienced of the NHS as she was. Therefore, the only way to attract, and avoid alienating, service users to the TSSP Management Group was to recruit those who were used to working on committees and had the confidence to voice their opinion in a formal meeting setting with a large number of professionals in attendance.

On a number of occasions while I was working at the TSSP offices, attending to user involvement tasks, Jackie would update me on the progress of recruiting stroke survivors to the TSSP Management Group. Hanging up the telephone, having just spoken to a stroke survivor, Jackie excitedly said to me one afternoon, ‘I’ve just spoken to a lady about the stroke get-together and I think she would be really good for the project management team’; Another time while we were eating our lunch she told me about a man she had visited following his attendance at the stroke get-together:

> I visited a man about the get-together and he was really articulate and had some really useful insights about stroke and I think he would be really good for the project management group.

At the first stroke get-together I observed Mary making a beeline towards Steve who was attending the event with his father who had had a stroke. During the morning session of the get-together Steve had been quite vocal about the TSSP, asking challenging questions of the TSSP personnel: ‘What happens when a good suggestion is made [by a service user]? Who will it be fed to? How will we know what has happened?’; and ‘What happens today must change the system otherwise it’s [the TSSP] a waste of time’. Mary thought that Steve’s combination of cynicism toward the NHS and the TSSP, yet positive attitude to want to actively change things for people with stroke would be great for ‘shaking up’ the TSSP Management Group. Steve told Mary he would think about it. But to Mary’s disappointment Steve later telephoned her to decline taking part in the TSSP Management Group. Mary reported that Steve said he wanted to be involved in something more practical to help stroke survivors, rather than being embroiled in committee meetings which would not have an immediate impact on stroke survivors' lives. During the get-together Steve had talked of his father's isolation since his stroke and how he wanted to do something practical to help stroke survivors. He said that he would like to volunteer to drive a minibus to take stroke survivors on a weekly outing, for example to the local library and cafe, to ensure that they had some human interaction and one good meal each week. Service users, therefore, who, during face-to-face meetings or telephone conversations, appeared to be articulate, were prepared to speak their mind and had experience of committee style work were identified as the 'right' kind of person to join the TSSP Management Group.

For the Training Health Care Professionals user group stroke survivors from as many different ethnic backgrounds as possible were encouraged to sign up. Within this user group Jackie planned an activity, known as 'Patients as Teachers'[24], to produce a DVD of stroke survivors' experiences of health and social care which would be used in training sessions for health care professionals. Typically Jackie would say to me, 'We must try to get Mrs Ozan [a Turkish lady I was in contact with about the stroke get-together] on board for the Patients as Teachers project.' During the stroke get-together she had told participants: 'We want as many of you as possible from all the

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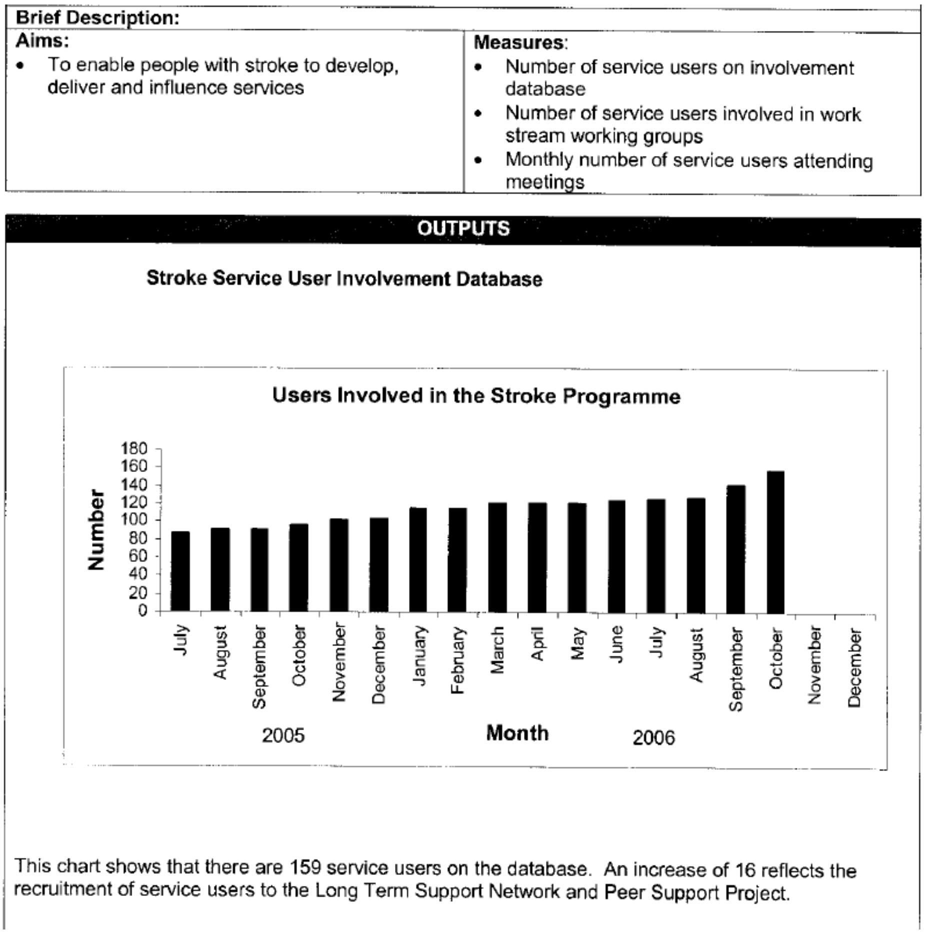
[24] Patients as Teachers is a model that seeks to use patient experience to train healthcare professionals in more sensitive treatment of and relationships with patients (Wykurz & Kelly 2002).

different communities and cultures across Lambeth and Southwark to sign up to this [Patients as Teachers] project'.

In this user involvement activity, which involved creating a product to be used in training NHS staff, I observed a need for a broad representation of stroke survivors in terms of ethnicity and disability after stroke, consistent with NHS wide concerns with diversity. I also noticed this attention to diversity throughout my time working on the TSSP. On one occasion about two years into the project, during a TSSP Management Group meeting, a conference to 'celebrate the success' and 'share the learning' from the three transformation projects was discussed. One PCT manager said there needed to be a good representation of the diversity of ethnic groups in the two boroughs on any visuals used in the conference (posters, power point presentations, hand-outs etc.). Kartik, a stroke survivor who had joined the Management Group as a service user representative, infuriated by this comment, suggested sarcastically that perhaps there could be some diversity in the Management Group. As it was Kartik, was the only non-white member of the TSSP Management Group.

I suggest that these strategies were adopted as a way of managing user involvement and making sure it was 'successful'. The success of user involvement in the TSSP was measured quantitatively by the number of stroke survivors who had agreed to become involved in the project. Each month Jackie was required by the funders of the TSSP to submit a report detailing the numbers of stroke survivors involved in the TSSP. Jackie's target was to demonstrate that the number of stroke survivors involved in the TSSP was increasing monthly (see Figure 6.2, overleaf). Therefore, strategies to sustain stroke survivors according to the specific user involvement task were required.

How stroke survivors had been involved in the project and whether they were influencing the project appeared to be of less interest to TSSP funders. The style of reporting Jackie was required to carry out reflects how user involvement was expected to fit into the existing NHS structures of meeting targets and reporting and measuring productivity based on numerical data (Black *et al.* 2006).



Brief Description:

Aims:	**Measures:**
- To enable people with stroke to develop, deliver and influence services	- Number of service users on involvement database - Number of service users involved in work stream working groups - Monthly number of service users attending meetings

OUTPUTS

Stroke Service User Involvement Database

This chart shows that there are 159 service users on the database. An increase of 16 reflects the recruitment of service users to the Long Term Support Network and Peer Support Project.

Figure 6.2 Extract from a User Involvement Working Group monthly reporting form (October 2006)

In this section I have described how the policy of user involvement was interpreted and then implemented and how stroke survivors were involved in the TSSP. The stroke ‘get-together’ was the main mechanism to invite stroke survivors to participate in the TSSP. Encouraging stroke survivors to ‘get involved’ in the TSSP required substantial efforts on the part of those of us responsible for implementing user involvement. Over a three-month period Jackie, I and TSSP administrators contacted stroke survivors, explained the TSSP to them and why their input was needed, and persuaded them to attend a ‘stroke get-together’.

Implementing stroke survivor involvement in the TSSP was interpreted as involving stroke survivors in decisions about health services, but the idea that user involvement practices should transform patient and professional roles was less explicitly articulated. In the following section I discuss user involvement practices within the TSSP and the areas of service improvement stroke survivors were involved in. I explore three factors which determined how these practices were enacted. As I go on to show, these practices served to maintain patient and professional boundaries, thus inhibiting the transformatory potential of user involvement.

6.2. User involvement practices in the TSSP

By June 2005, three months after the two stroke get-togethers had taken place, three 'user groups' (Peer Support, Information, and Training Health Care Professionals) had begun to regularly meet. Of the available ways to participate in the TSSP, the Information and Training Health Care Professionals groups were by far the most popular with stroke survivors, having up to 15 stroke survivors regularly attending monthly meetings. Peer support was less popular, with only four stroke survivors initially signed up to receive training to offer peer support to newly diagnosed stroke patients. Not a single stroke survivor expressed any interest in joining the User Involvement Working Group to help oversee the implementation of user involvement within the TSSP. Five people had been approached, or had volunteered, to become members of the TSSP Management Group. However, of the five stroke survivors who underwent training[25] to participate in the TSSP Management Group only two retained their membership throughout the project's lifetime. Throughout the course of the project three further stroke get-togethers were held to report to stroke survivors the progress of the project and to continue to encourage stroke survivor involvement.

The TSSP succeeded in engaging stroke survivors and enacting involvement to produce a range of outputs aimed at improving specific components of stroke care. Figure 6.3,

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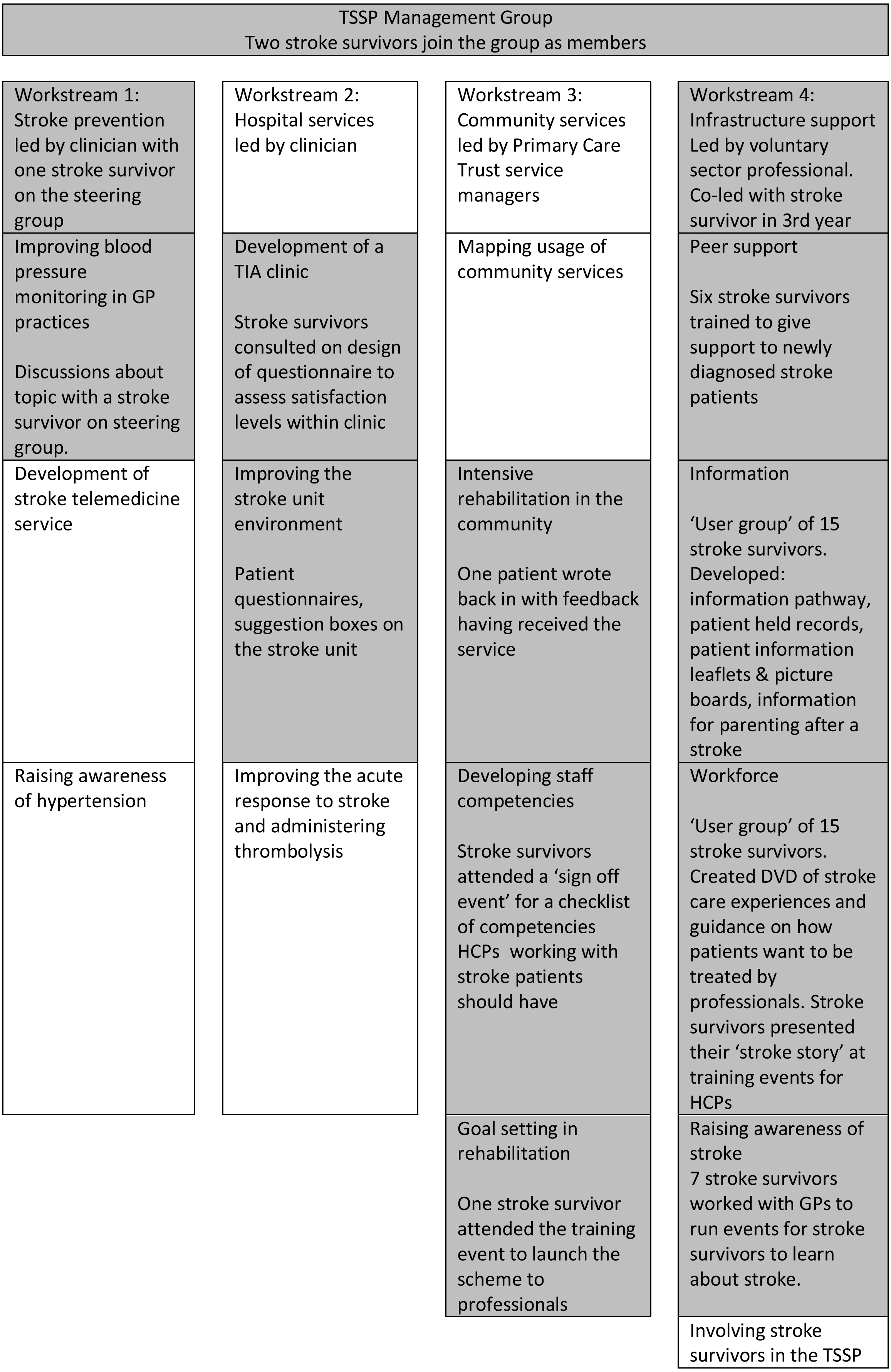
[25] All five service users attended 4 'training' sessions designed to familiarise them with the aims and structure of the TSSP and the language and jargon used in the TSSP Management Group meetings.

overleaf, provides a visual representation of the structure of the TSSP and the user involvement-related activities which took place within the four workstreams over the three years of the project’s duration. The figure lists service improvement activities undertaken within each workstream. Activities highlighted in grey are those which incorporated stroke survivor involvement. However, the degree of stroke survivor input and involvement varied considerably between the activities within the four workstreams.



TSSP Management Group
Two stroke survivors join the group as members

Workstream 1: Stroke prevention led by clinician with one stroke survivor on the steering group	Workstream 2: Hospital services led by clinician	Workstream 3: Community services led by Primary Care Trust service managers	Workstream 4: Infrastructure support Led by voluntary sector professional. Co-led with stroke survivor in 3rd year
Improving blood pressure monitoring in GP practices Discussions about topic with a stroke survivor on steering group.	Development of a TIA clinic Stroke survivors consulted on design of questionnaire to assess satisfaction levels within clinic	Mapping usage of community services	Peer support Six stroke survivors trained to give support to newly diagnosed stroke patients
Development of stroke telemedicine service	Improving the stroke unit environment Patient questionnaires, suggestion boxes on the stroke unit	Intensive rehabilitation in the community One patient wrote back in with feedback having received the service	Information 'User group' of 15 stroke survivors. Developed: information pathway, patient held records, patient information leaflets & picture boards, information for parenting after a stroke
Raising awareness of hypertension	Improving the acute response to stroke and administering thrombolysis	Developing staff competencies Stroke survivors attended a 'sign off event' for a checklist of competencies HCPs working with stroke patients should have	Workforce 'User group' of 15 stroke survivors. Created DVD of stroke care experiences and guidance on how patients want to be treated by professionals. Stroke survivors presented their 'stroke story' at training events for HCPs
		Goal setting in rehabilitation One stroke survivor attended the training event to launch the scheme to professionals	Raising awareness of stroke 7 stroke survivors worked with GPs to run events for stroke survivors to learn about stroke.
			Involving stroke survivors in the TSSP

Figure 6.3 User involvement-related activities implemented within the TSSP

Despite the original aim to involve service users throughout the TSSP, in practice over the three years of the project, user involvement activities were mainly focused on the TSSP Management Group and the fourth ‘infrastructure workstream’ (focussing on improving stroke information, training stroke health care professionals and peer support). In the three other workstreams (stroke prevention, hospital services, and community services) the involvement of stroke survivors tended to be limited to one-off meetings where stroke survivors were consulted on an aspect of service development, usually in the latter stages of a service improvement initiative.

I now explore three factors which influenced how user involvement practices were enacted, and which served to maintain patient and professional boundaries: professional hierarchies, patient-professional spheres, and replication of the ‘work’ environment.

Professional hierarchies

Jackie and I would often discuss her background and how she came to be working for the TSSP. During an interview she told me:

> I didn't know that I was going to be asked to lead on user involvement. But I did a presentation, my presentation in my interview was on user involvement, and so they thought, “we'll ask her to lead on user involvement”.
>
> Interview with Jackie, 7th April 2006

The appointment of a user involvement lead and establishing the UIWG - a specific group responsible for the implementation of user involvement - meant that user involvement became a distinct activity within the TSSP. Embedding user involvement throughout the project, an early aim of the TSSP, was harder to achieve. Over lunch or whilst travelling to meetings or to meet stroke survivors, Jackie and I would frequently discuss how to resolve this issue. Jackie described her situation as a ‘catch 22’. Whilst it was necessary to have a dedicated person responsible for user involvement, the existence of the position meant that her colleagues could leave ‘doing user involvement’ up to her. Jackie could encourage colleagues working in the other workstreams to involve stroke survivors in service improvement work, but she did not have the authority to require it or control the form that user involvement activities took.

Unsurprisingly, perhaps, user involvement was most developed in the fourth infrastructure workstream (see Figure 6.3), a workstream overseen by Jackie and other professionals with a background and political commitment to user involvement. Professionals responsible for involvement and those happy to undertake involvement activities with stroke survivors tended to have backgrounds in the voluntary and social care sectors and tended not to be involved in the more clinical and technical aspects of the TSSP. These professionals displayed a moral and political commitment to the ethos of involvement: a belief in the engagement of citizens in public decision-making and promoting patients’ expertise as valid as that of professionals.

In comparison, the other three workstreams (stroke prevention, acute and community services) were managed by senior clinicians. User involvement activities undertaken in these discipline specific workstreams tended to be the responsibility of GPs and therapists and took a more passive form, favouring the use of patient satisfaction surveys and suggestion boxes or consultation with stroke survivors in the later stages of service development improvements. Hence a range of interpretations of ‘user involvement’ existed within the organisation based on the professional and philosophical backgrounds of those working within each of the four workstreams of the TSSP.

Implementation of user involvement in the TSSP, therefore, not only did little to transform patient and professional relationships but served to reinforce professional boundaries within the organisation. Participant observation of the implementation process reveals a more subtle and nuanced reading of power than the policy literature assumes. In this case, power was not uniformly held by professionals over patients. Within the category ‘professional’ sub categories of professionals had differing abilities to influence the implementation of stroke survivor involvement. The appointment of Jackie, a middle ranking NHS manager, as the lead for user involvement absolved other categories of professional, particularly senior clinicians, of responsibility for implementing user involvement activities within their areas of service improvement. This further inhibited the potential for partnership between health care professionals (as a category of NHS professional) and patients.

Replicating the ‘work’ environment

In chapter 5, I described the TSSP offices and the lack of disabled access (see Chapter 5, section 5.2). Meetings with stroke survivors, by necessity therefore, were held ‘off site’ usually at the offices of one of the local stroke–related charities. Whilst a little inconvenient, as external meeting rooms had to be found and booked, this did not seem problematic for those implementing user involvement since ‘best practice’ guidelines for user involvement advise that activities involving service users are held in a neutral environment (Hanley & Staley 2005;Together 2006). Guidelines recommend that meetings are not held in a hospital setting as this may bring back ‘painful’ memories for service users (Hanley & Staley 2005). Guidelines further recommend that meetings should not be held in the professionals’ place of work as this puts professionals at an advantage. However, I shall argue that holding meetings away from the place of work and the decision-making arena limited stroke survivors’ full involvement in the TSSP as Anita’s story reveals.

Anita, had her stroke in her late 40s, and for short period of time was a member of the TSSP Management Group. Prior to her stroke Anita had worked in social care and had experience of sitting on committees – one reason why she thought she was able to participate in the TSSP Management Group. However, after the second meeting she attended she had the sense that professionals on the TSSP were not ready to listen to patients’ views. Furthermore the decision-making process seemed unclear to Anita. During an interview, Anita said that she would have expected that at management meetings decisions to be put to a vote, ‘but that's the second meeting [I’ve been to], and I haven't seen the chair say “we'll vote on it”.’ Anita said that she felt that decisions about the TSSP were made outside of the TSSP Management Group meetings, without the presence of stroke survivors. Anita said she realised that most members of the TSSP Management Group were employed by, or seconded to, the TSSP, putting them at an advantage in terms of understanding and participating in the project. Anita commented that in contrast to her and the other stroke survivor members, TSSP professionals on the Management Group ‘know what they are going to talk about’ at the meeting and ‘also they communicate on the internet, they are on the phone, and some of them are working in the same department so they have time to explain [the work] to each other.’ Therefore, the transitory nature of Anita’s involvement, restricted to monthly TSSP Management Group meetings held in a ‘neutral’ environment, limited her contribution to making decisions about the project, particularly as professionals employed on the TSSP had other opportunities to meet up and discuss the project.

Earlier in the chapter, I introduced the idea that a particular type of stroke survivor was deemed suitable for certain types of involvement (see section 6.1 ‘Encouraging stroke survivor involvement’). This belief was not limited to professionals on the TSSP, but was a view held by some stroke survivors themselves. The theme of representation and the type of service user suitable was particularly evident in the problem of sustaining stroke survivor involvement in the TSSP Management Group, where only two of the five original recruits to the TSSP Management Group maintained their participation beyond two meetings.

It was a theme which arose in interviews I conducted with William and Kartik – the two service users who most regularly attended the TSSP Management Group. William cared for his wife Matilda who had had stroke. Complications with the stroke and other co-morbidities meant that she was confined to a wheelchair. William was in his 80s and had a background in industry and business. Up until the stroke both William and Matilda had run a consultancy business. Kartik's background was in education and he worked in a local education authority at the time of his stroke. Kartik had his stroke in his 40s, and although he would not describe his stroke as severe, the amount of paid work he was able to do since his stroke had been curtailed. Since his stroke, Kartik had taken on the role of house husband looking after four school-aged children along with doing some consultancy work.

William thought that the nature of stroke gave people a 'very personalised' view of stroke, incompatible with the demands and the professionalised nature of the TSSP Management Group.

> William: It goes back, what you said very early on, about people straying from the point, I think most people who have had a stroke they have a very personalised view of lots of things, as I say, and I found this with some of [the user] groups, not so much the TSSP Management Group, because there aren't many people who have had strokes on that, but I mean on some of the other [user groups], people always want to concentrate on their own experience, rather than looking at the broader picture
>
> Interview with William, 2nd March 2006

Kartik's view differed from William's. Kartik said that he had the sense that the TSSP did not want people with stroke struggling to communicate in the TSSP Management Group meetings which is why they had not asked people who were more severely affected by stroke. Kartik – intelligent, articulate, and without any stroke communication disability – said that he felt he was seen as a 'good bet'.

In her analysis of parent participation in implementation of a service delivery framework for children's mental health in the United States, Potter (2010) describes the ‘wrong parents’ and ‘right parents’ considered suitable for lay involvement. Both parents and professionals participating in the service delivery programme classified ‘wrong parents’ as those who were only concerned for their own child, were unable to move beyond their own personal issues, or those who had a visible mental health problem. ‘Right parents’ suitable for lay involvement by contrast were those who could not only provide an experiential voice but also identify gaps in mental health services and the collective needs of other families, and hold mental health service professionals and the system to account (Potter 2010).Thus as I have reported from the TSSP, Potter (2010) found that in order to foster partnerships between patients and professionals, lay participants were required to possess additional, civic-based skills, beyond those needed in the service delivery arena relating to their lived experience of health care and services.

As I have alluded to already, this channelling of people to certain activities can be seen as a way of protecting or safeguarding the user involvement project. A number of times throughout the course of establishing user involvement, Jackie and Mary discussed the problems that might arise if ‘unsuitable’ people were recruited to join the TSSP Management Group. Mary feared they would become disillusioned and drop out if they could not penetrate the TSSP Management Group or felt that they were not being listened to. This suggests that a balance between having service users and not alienating them once they are involved is required, particularly if the organisation’s style of working is unlikely to change to accommodate service users.

This finding, that patients and members of the public were manoeuvred into positions that professional thought most appropriate, resonates with findings from a study of public participation and collaborative governance by Newman *et al.* (2004). In this interview and observational study, the authors explored processes of participation in a range of forums to engage local citizens in decisions about local health, social care and community services. The dominant discourse amongst officials promoting citizen engagement was of a public needing to be empowered in order to engage effectively rather than services needing cultural change to engage with the public successfully. Furthermore, public participation was enacted using the 'norms of bureaucracy', incorporating local citizens into official institutions (Newman *et al.* 2004).

User involvement activity within the 'norms of bureaucracy' seems to encourage a certain type of patient or citizen to participate, those who feel comfortable with the meeting or committee format. In interviews with stroke survivors involved in the TSSP, a number of people cited their previous experiences of being involved in committee work as a reason for believing they had the skills to participate in the TSSP. The vast majority of those actively involved in the TSSP were regular volunteers for local community groups and organisations such as school governors, church committees, befriending schemes. One limitation of making user involvement practices fit within the organisation is that participation of the 'good' or 'active' citizen is favoured and questions are raised concerning community members who fail to fit this model (Cowden & Singh 2007) and those who actively decline to participate.

This was something I personally felt during interviews with stroke survivors who had attended the stroke get-together but who had declined to participate further in the TSSP.I felt uncomfortable conducting these interviews to understand their decisions *not* to participate. As the interviewees listed their reasons for not participating, I felt my questions, to find out why they had not wanted to join one of the user groups, were a direct criticism of their decision not to participate, which I was forcing them to justify.

Cowden and Singh (2007) further note that an underlying problem with the user involvement project, as promoted by the New Labour government, concerns who represents the sections of society not even granted the status of 'citizen', such as asylum seekers and those with severe mental health problems (Cowden & Singh 2007). In the TSSP those unable to leave their homes or care institutions were excluded from the project by the nature of involvement activities taking place in the public domain of a meeting or user group format. The grievances and interests of these groups were therefore prevented from being heard.

Patient-professional spheres

As I suggested at the start of this chapter, user involvement policy implies that the traditional roles of patient and professional require a reconceptualisation if the 'new working relationships between patients and professionals' and a 'model of partnership' as required of the policy (Department of Health 2001c: 3; Department of Health 2001b: 27). However, as the following stories illustrate, this reconceptualization on the part of professionals was not easy to achieve.

Early on in the process of inviting and encouraging stroke survivors and their relatives to the project I went with Sarah (a TSSP administrator who led the Information user group) to visit Mrs James. Mrs James, was originally from Africa, in her 70s, and cared for her husband who was wheel chair bound following a stroke. They attended a number of stroke get-togethers as a couple along with their grandson, but appeared less keen to join any of the regular 'user groups'. Mrs James' main concern, which she described at the get-togethers, was her housing situation. She and her husband, were living in the top floor of a high rise block of flats with lifts that worked intermittently, making it impossible for them to leave the flat in case, on their return, the lifts were broken and they could not get back up to their flat. Using the stairs was out of the question for Mr James.

I met Sarah at the TSSP offices so that we could travel to Mrs James' home together. Sarah told me that she had tried to rearrange the visit for another day as it turned out it was Mrs James' birthday. However, Mrs James had insisted that we come as arranged. Sarah explained how she had wanted to bring Mrs James some flowers for her birthday, but had been advised not to. Jackie, over hearing our conversation, joined in confirming that arriving with flowers was not appropriate as it would blur the relationship between patient and professional. Mrs James might start to see us as friends, making it harder to keep professional distance especially if she started to ask us to do things for her. However, despite Jackie's concerns about 'doing things' for stroke survivors, it may have been due to Mrs James 'involvement' in the TSSP through her attendance at the stroke get-togethers that she was able to resolve her housing situation. Mrs James repeatedly told her story to some senior social care managers who were present at one of the stroke get-togethers. One told her who she needed to telephone ‘to get things sorted out’ and then gave her his business card. He told her to contact him directly if she ‘still didn’t have any luck with getting things sorted out’. Eventually, Mrs James and her husband were rehoused in a ground floor maisonette with a garden and Mrs James declined to participate further in the TSSP. Attending the stroke get-together had enabled Mrs James to speak directly to senior social care managers who listened to her story and helped her navigate the system to start the process to be rehoused. In this sense, implementation of user involvement had altered the relationship between professionals and patients, but perhaps not in the way envisaged by policy makers.

About a year into the TSSP, stroke survivors involved in the Information user group ran a number of ‘Stroke Raising Awareness Events’ at local GP practices. The purpose of these events was to provide stroke patients at a GP practice with information about stroke – information that would be delivered by both health care professionals and stroke survivors. Stroke survivors from the Information user group attended the event to recount their experience of stroke to the audience and answer questions about how they coped with the stroke and its impact. At one of the Raising Awareness Events, Jackie and I met the five stroke survivors who were to present that day in the reception area of the GP practice. Jackie 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 Jackie through a side door into the larger room where the event was going to be held. The rest of us got up and followed Jackie, one of the group following in her electric mobility scooter. On reaching the side door we were stopped by the receptionist, who told us that the event was not due to begin for another hour or so. Jackie had to explain to the receptionist that we were all part of the event team. She further explained that although some of the team had had strokes they were not patients from the GP surgery wanting to attend the event. With a bemused and suspicious look the receptionist reluctantly let us all through.

The two stories cited above illustrate the difficulty professionals had to reconceptualise the traditional category of patient to accommodate the notion that service users have a contribution to make to service planning and development. In the first story, Jackie was keen to ensure that the relationship between Mr and Mrs James and TSSP staff remained that of patient : NHS professional. In the second story receptionists at a GP surgery found it hard to comprehend the idea that stroke survivors, who they saw as patients, were able to deliver a Raising Awareness Event on a par with professionals. Despite the policy rhetoric that patients should be *partners* in the NHS, in the TSSP stroke survivors remained as patients even though most stroke survivors were not actually receiving stroke services at the time of their participation in the project.

In this section, I have discussed three factors which influenced how user involvement was implemented in the TSSP and which served to maintain traditional boundaries between patients and professionals. The analysis reveals the professionalised nature of user involvement practices. User involvement as implemented in this setting served to reinforce professional hierarchies within the NHS. TSSP professionals responsible for, and most engaged in, user involvement activities tended to be from the social care and voluntary sectors or lower down the hierarchy of the organisation, such as administrators or lower grade managers. Fewer health care professionals participated in user involvement activities and those who did tended to be therapists and nurses. Thus, user involvement activities tended to be most prevalent in the non-clinical workstreams.

User involvement activities had to fit within a ‘work’ environment, taking the form of established NHS work practices such as meetings and committees. This was advantageous to professionals and those stroke survivors who were used to meeting or committee environments, but excluded those service users who had no experience of interacting in this way. Despite policy rhetoric for patients to become partners in designing NHS services, stroke survivors and professionals in the TSSP remained in their traditional spheres and roles.

6.3. Stroke survivor experiences of involvement

In the previous section I primarily focused on professionals’ views of user involvement and how their roles within the TSSP and their professional backgrounds influenced the implementation of user involvement policy. I now turn to stroke survivors’ views of user involvement policy, what they thought of the TSSP and their role within the project. I argue that the policy objective to transform patients and professional relationships was not one shared by stroke survivors. I explore stroke survivors' experiences of involvement through three themes: the traditional patient role, knowledge, and creating a sense of community.

Traditional patient role

As I discussed above, whilst TSSP user involvement activities were not enacted within an NHS setting, such as a hospital or clinic, many stroke survivors saw the 'user groups' or user involvement-related activities as an extension of the health service and retained their traditional patient role. On one occasion, Simon, a service improvement facilitator, attended the Information user group to talk about a TIA[26] clinic and a questionnaire he had designed to assess how the clinic was working from the perspective of patients attending the clinic. After Jackie had introduced Simon to the group, Simon handed out the questionnaire to each of the group members sitting round the large meeting room table. He explained that he had 'brought it [the questionnaire] to you guys' to see if it was understandable and the right way to 'check patient feedback.' The Information group members started to flick through the questionnaire but appeared confused about what they were meant to do with the questionnaire they had just been handed. Some took out pens from their bags and

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[26] Transient Ischaemic Attack or 'mini-stroke' is a neurological event similar to a stroke but with symptoms lasting for only a short period of time. If not treated, there is a high risk of having a major stroke in the near future.

started to fill in the questionnaire, giving it back to Simon once they had answered all the questions. Others said they did not see how the questionnaire was relevant to them since they had not had a TIA or been to this clinic before. Nora, similarly feeling the questionnaire was not relevant to her, said that she would take the questionnaire home and ask her husband, who had had a mini-stroke, to fill it in.

This story illustrates that involved stroke survivors tended to perform a passive role as providers of information rather than performing a more active role to develop how the information may be acquired in the first place. It further demonstrates the problematic nature of consulting with service users as a one off activity once the majority of the work has been completed. The stroke survivors present may have been able to contribute more fully to a discussion on the best way to set up a clinic for TIA patients if they had been involved in earlier discussions about clinic plans.

Whilst in the above story stroke survivors maintained their traditional role as a patient, other stroke survivors participating within the TSSP did begin to adopt an ‘expert’ role. This was particularly the case with stroke survivors involved in the Training Health Care Professionals user group. Jackie, who ran this user group, encouraged stroke survivors to see their experience of stroke – their ‘experiential knowledge’ (Caron-Flinterman *et al.* 2005) – as a valid form of expertise which could be harnessed to teach health care professionals how to care for stroke patients. Stroke survivors were encouraged in the Peer Support user group to see themselves as experts in ‘living with stroke’ and able to pass on this expertise to those newly diagnosed with stroke. Consequently a group of seven stroke survivors participating in the two aforementioned user groups were invited to take part in an additional user group to develop Stroke Raising Awareness Events held at GP practices.

Carmen was one of the stroke survivors who took part in planning and presenting at a number of Stroke Raising Awareness Events. Carmen was originally from Jamaica and in her 70s. She was softly spoken but overcame nerves and shyness to talk about her experience of living with stroke to other stroke survivors. However, whilst she adopted this new role as an expert on living with stroke she maintained that doctors have an important role to play in a patient’s healthcare. In an interview[27] I asked her how she thought the TSSP was benefiting from having people like her taking part in it:

> Carmen said that through the TSSP, people in the user groups were starting to understand and think about ‘what can I do to help?’ Carmen continued talking about the ‘good doctor’ and that ’you have to know how to work with’ your doctor. ‘You got to be, think about yourself, love yourself, know that they [the doctor] have many things [to do], they cannot do it all, help yourself and then they respond.’ Carmen said if you do that, then your doctor cares: ‘You have to know how to deal with your doctor’. She said that some patients make it like they know more than their doctor but you can’t do that either otherwise they won’t help you. And you’ve got to take your medication. Carmen said, ‘It’s like a job, we have to all work together’. ‘If you don’t take your medication you’re going backwards’. Carmen said that ‘you shouldn’t rely on your doctor alone’.
>
> I asked Carmen what had been the positive things for her taking part in the TSSP. Carmen replied that it was the chance to ‘see others, listen to each other’ and that ‘we’re instructed by people who are interested and who care’. Then Carmen started to tell me about what it is like experiencing a stroke in another country. Her husband had a stroke in Jamaica where there was no such thing as the TSSP, and when you see what the services are there you realise that we are very lucky with what we have here. Carmen said that she would like to see things reach a point that you people [health care professionals] realise that you are doing good.

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[27] This interview was not tape recorded.

Interview with Carmen, 13th March 2006

Similarly, Jim stated that taking part in the TSSP and meeting for the first time other people who had a stroke and listening to their stories prompted him to investigate his own stroke story. For the first 18 months after having a stroke Jim was not aware of what had happened to him or the decisions doctors and family members had taken about his treatment and care. Jim visited his GP to ask for a copy of his medical records so that he could read about what had happened to him in this period of his life which he could not recollect.

These two stories highlight the transformation of patient roles user involvement policy is hinting at. Carmen and Jim had adopted a role of taking responsibility for their health but within the confines of medical expertise provided by health care professionals. Jim required that his story be verified through consulting the official medical record and Carmen advocated patients taking responsibility for their health but with instruction from health care professionals. Through the lenses of biosociality and biological citizenship, Carmen and Jim were forming an identity around a good, responsible, informed citizen (Rose 1997).

Lukes' framework can help to explain why stroke survivors involved in the TSSP may have been reluctant to relinquish their traditional patient role. The third dimensional view of power advances the two-dimensional view with a focus on non-observable power and why things do not occur. Lukes (2005) argued that power is exercised by preventing people from feeling they have grievances in the first place. This occurs though the shaping of perceptions, beliefs and preferences in such a way that they accept their role in the existing order of things and are not aware of their grievances.

Throughout my fieldwork stroke survivors and carers of those who had had a stroke could clearly identify the problems and grievances caused by the stroke and which were made harder to overcome due to the response from the health service and structural factors within society, for example, lack of health and social care services, problems with public transport, isolation and community change, poor and unsuitable housing. Whilst stroke survivors had and could articulate their grievances, and some could suggest solutions for these, there was a degree of acceptance of the status quo that not all problems would be addressed by the TSSP. There were few examples of stroke survivors trying to push for solutions to problems that the TSSP was not going to address, despite indications in the early TSSP proposal documents and newsletters and at stroke get-togethers that stroke survivors would have full involvement in, or control over, decisions about stroke services.

A possible explanation for this is the traditional role of the patient not to question or challenge the doctor or professional looking after them. It is a relatively recent proposal, over the past decade, that patients should play a role in decisions about their own health (Department of Health 2001d;Department of Health 2005a;Scally & Donaldson 1998). Redfern *et al.* (2006) highlight the limitations of a patient centred approach to healthcare through observations of stroke prevention and risk management in a stroke clinic. They cite social and structural limitations of healthcare which influence a patient-centred approach to secondary prevention delivery: medical authority, and its constraints on patients' ability to voice concerns within the consultation; structural barriers relating to service organization; and expectations of the patient role (Redfern *et al.* 2006). To complement the discussion on patient roles I now examine how different forms of knowledge within the TSSP maintained patient and professional domains.

Knowledge

The initial encounters I had with stroke survivors attending the 'get-together' (see section 6.1 'The stroke get-together') illustrated the variety of reasons people had for attending: to increase their own medical knowledge about stroke, to find out about stroke-related services and how to access these, and to share acquired knowledge to help others who had had a stroke. These reasons point to some of the theoretical questions concerning the value of different forms of knowledge which come to the fore in encounters between professionals and patients. Mr Todd, for example, during the first stroke get-together expressed particular concern that a doctor should have attended the meeting. After the stroke get-together he told me that 'it would have been better if there had been a doctor here today to answer our questions on stroke'. This form of 'expert' knowledge provided by doctors was seen by Mr Todd as preferable to that of 'experiential' knowledge acquired first hand through the direct, lived experience of having a stroke. Ruby, who had also attended the first stroke get-together declined to participate further in the TSSP. During an interview I asked her why she declined to participate further and she told me that she did not think that she could help much as it was now five years since she had had her stroke and she did not think she ‘knew enough [about stroke]’ to help. User involvement is predicated on a notion of valuing experiential knowledge yet the reason Ruby gave me for not getting involved suggests that she does not attribute this type of knowledge as a worthy contribution, believing that it is ‘expert’ knowledge which is required. Irene’s motivation to attend the get-together, however, was to share her own ‘experiential’ knowledge that she had acquired through caring for her husband who had had a stroke. Irene’s motivation to participate was the most akin to user involvement philosophies as set out in policy literature[28] entailing notions of the good citizen and the value of experiential knowledge embodied by patients in comparison to expert knowledge embodied by doctors (Farrell 2004). The stories from these three stroke survivors attending the first stroke get-together illustrate the contrasting views within the TSSP regarding the value of patient knowledge. The views of stroke survivors such as Mr Todd and Ruby also provide contrast to patient activists from fields such as HIV/AIDS who came to believe in their own experiential knowledge and its contribution to furthering medical and scientific knowledge and service provision.

User involvement practices seek out the experiential knowledge of service users as a means to reduce professional power and increase lay power within the organisation. However, in the TSSP, types of knowledge and who had ownership over that knowledge determined how stroke survivors were involved in the project. Previously in

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[28] See Chapter 1, section 1.2 Accounting for the rise of user involvement for a discussion of these philosophies.

this chapter, I discussed two user involvement activities (raising awareness of stroke and training health care professionals) where stroke survivors' experiential knowledge was encouraged. TSSP staff therefore promoted experiential knowledge as useful for educating health professionals and supporting other stroke survivors. Expertise of stroke through experience was encouraged and acknowledged in terms of coping with the stroke after it has happened and living with the consequences of stroke, particularly once health services were no longer available. This domain of knowledge and expertise attributed to patients was most evident in the fourth workstream of the TSSP where user involvement activities were most prevalent.

Clinical service development was seen to require a different kind of knowledge. Consequently, in comparison to workstream 4, user involvement in the three clinically focused workstreams of the TSSP was limited to one-off activities (see Figure 6.3 for a diagram illustrating the user involvement activities taking place within the four workstreams of the TSSP). There is evidence that professionals believed service users would not be capable of participating in some aspects of the TSSP because they lacked the necessary technical or medical knowledge. For example, during a meeting with the TSSP manager and stroke service improvement facilitators, Jackie asked her colleagues why service users had not been involved in a project to map usage of community services. They responded suggesting that the work would have been too difficult and too complicated for service users to undertake.

Stroke survivors' beliefs about what caused their stroke were taken less seriously by TSSP professionals. One meeting of the Information user group was attended by a health promotion specialist who was employed by the TSSP to work on stroke prevention (workstream one). She attended the Information user group to discuss plans to have stalls at local community summer festivals to inform the public about the risks of untreated high blood pressure. These stalls would offer blood pressure tests and provide information about the causes and consequences of, and treatments for, high blood pressure. During her talk the health promotion specialist discussed high blood pressure as something which the individual could control through changing diet and eating healthily, taking exercise, stopping smoking, reducing alcohol intake and taking blood pressure medication. Pam, who cared for her husband who had had a stroke, as well as her grown up disabled son, said she thought it was the environment which ‘makes raised blood pressure’. She told her story of waiting for an ambulance to take her disabled son to an appointment at the hospital. The ambulance turned up late so they had had to ‘abort the trip’. Pam said that the stress of not knowing if they were going to make the appointment or not was so stressful for her husband that ‘you could actually see the blood pressure rising’. In this instance the health promotion specialist and Jackie acknowledged that the causes of high blood pressure were complex. On other occasions, however, stress brought on by inappropriate housing situations or navigating the complex health and social care systems as a contributory factor to high blood pressure was dismissed by others, particularly GPs associated with the TSSP.

This is perhaps not unsurprising given that connections between individual behaviour and the cause of stroke have been described in medical textbooks since the 1700s (Daneski *et al.* 2010). The current discourse in public health medicine is that it is the responsibility of the healthy citizen to participate in activities that reduce risks to health identified through expert knowledge (Daneski *et al.* 2010)[29]. Popay and Williams (1996) argue that the discoveries of bacteria in the nineteenth century gave rise to the medicalisation of public health through the dominance of the medical profession and the birth of epidemiology. This development whilst providing an explanation for diseases such as tuberculosis and cholera, reduced political commitments to solve social problems of the poor (Popay & Williams 1996). This pattern of medical, epidemiological knowledge dominating other explanations or forms of knowledge was evident within the TSSP.

Therefore, while user involvement policy is concerned with altering relationships between categories of citizens and professionals, the case of the TSSP suggests that professionals acted to maintain traditional patient/professional boundaries. While I have suggested a framework such as biological citizenship may be helpful to explore and understand user involvement practices, the way knowledge was utilised in the TSSP may also highlight some of the limitations of the theory. As other authors have suggested (see Fraser 2010), engaging with medicine and defining oneself according to

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[29] In May 2006 I attended the European Stroke Conference and was struck by one particular talk given by an Israeli clinician, Dr Tanne. In his talk the clinician referred to stroke patients who had made a link between stress leading to raised blood pressure, causing their stroke. Dr Tanne suggested that it was now time for the medical community to recognise this association and to explain it through biological reasoning. Recent editorials in medical journals are calling for a move away from looking at the medical causes of disease to investigate some of the societal or structural causes of ill health such as social cohesion (The PLoS Medicine Editors 2010) despite this being an old debate amongst social scientists.

a biological identity does not help solve problems of a non-medical nature, such as housing. The TSSP was focused on stroke health services, but a number of the concerns raised by participating stroke survivors related to problems beyond the medical aspects of stroke such as isolation, housing problems, and transport. In the final section of this chapter I build on this theme of isolation and community.

Creating community

In Chapter 5, I referred to a common theme of isolation and community change which arose during conversations with stroke survivors either during participant observation or formal interviews (see section 5.2 Community and isolation). Maureen was a stroke survivor who had attended one of the first stroke get-togethers. She had spent time in the stroke unit at St Thomas' Hospital, and during my interview with her, commented on how hospital care for stroke patients was isolating. She said that you 'see it in hospital: people sitting in rooms all on their own with no one to talk to'. When I asked her what she thought about the government's drive to encourage patients to play a role in the development of health services she said that what she thought the government should be doing is 'getting people to talk to each other more'. During interviews and informal conversations, stroke survivors frequently remarked that it was through their involvement in the TSSP that they had the chance, often for the first time, to meet other stroke survivors in a similar situation to themselves, as Jim's quote illustrates:

> Well as I said before, it [participating in the TSSP] made me go to my doctor and find out as to, you know, what happened to me when I had a stroke, which I probably wouldn't have bothered to do. Apart from the fact of hearing of other people's

> experiences of stroke cos I mean the people there, the experiences are so different…so that was a positive thing for me to sort of go and find out… yeah and you know meeting people and finding out about their experiences. It's nice to meet new people isn't it?
>
> Interview with Jim, 25th January 2006

Maureen's comment about what she thought the government should be doing to reduce isolation and stroke survivors' positive reports of meeting others stroke survivors suggests that people felt that a sense of belonging was an expected or necessary outcome of involvement in the TSSP. However, some stroke survivors I interviewed identified the lack of community within user involvement activities as *limiting* involvement. They compared their experience of participating in the TSSP with other experiences of 'involvement' through Neighbourhood Watch Schemes, their church community, and Parent Teacher Associations in schools.

Phyllis, was a foster carer in her early 50s and classed herself as 'at risk of stroke' due to high blood pressure, diabetes, and a family history of stroke. Initially she had become involved in the TSSP to support her friend, Carmen, who had had a stroke, but who had not been confident enough to attend TSSP user involvement activities alone. Both women became particularly active in the Information and Training Health Care Professionals user groups. During an interview, Phyllis discussed the importance of social events such as a 'day out in summer, seaside or something' to make you 'feel you're involved'. To illustrate her point, Phyllis told me about her Neighbourhood Watch group and how as a group they would socialise together, doing things such as going out for a meal. I had a similar discussion during an interview with William, the carer on the TSSP Management Group, and his daughter-in-law, Michelle. William compared his experience of involvement in the TSSP compared to his experiences of lay involvement in the Church.

William had been involved in the Church since 1940 where he met his wife Matilda through one of the church youth clubs. He had been involved in parish councils and various lay roles within the Church administration. William compared his involvement in the Church to that of the TSSP, feeling greater engagement with the Church because ‘you’ve got yourself involved in the church through basically a spiritual commitment and it grows from there.’ Michelle echoed these sentiments:

> You’d also socialise, wouldn’t you, in other committees. You’d know each other because of other things. Yes, in the church or the Parent Teacher Association or something like that, you’d kind of get to know each other because you’ve got something in common and you socialise and then out of that comes something.
>
> Interview with Michelle, 2nd March 2006

Despite the NHS being important to most people in the UK, stroke survivors involved in the TSSP appeared not to feel the same affinity compared to other institutions they may be involved in such as the Church or education. The professionalised nature within which user involvement was enacted, which I discussed in previous sections of this chapter, raises questions about the limited nature of ‘community’ that was desired but not achieved. This also suggests that biosociality - a social group based on a biologically determined identity such as ill health or a susceptibility to ill health - may not be enough to cement and sustain groups, despite Rabinow’s predictions (2008).

6.4. Conclusion

The implementation of user involvement policy in the TSSP was shaped by TSSP professionals’ and stroke survivors’ interpretations of the policy and their interactions with one another. Despite policy rhetoric for patients to become partners in designing NHS services, stroke survivors and professionals in the TSSP remained in their traditional spheres and roles. User involvement was not viewed as a mechanism to transform relationships between patients and professionals and transfer power to patients as indicated in the policy.

Initially stroke survivors were positioned as ‘partners’ in the project to transform and modernise stroke services. However, the parameters of the partnership were determined from the outset by professionals in the TSSP. The stroke ‘get-together’ was the main mechanism to invite stroke survivors to participate in the TSSP. Encouraging stroke survivors to ‘get involved’ in the TSSP required efforts on the part of professionals to contact stroke survivors, explain the TSSP to them and why their input was needed, and persuade them to attend a ‘stroke get-together’ where they would be able to find out more about the project and ‘ways to become involved’. The areas of stroke service improvement available for stroke survivors to participate in had been determined by professionals, despite some stroke survivors at the stroke get-together raising their own concerns regarding areas of stroke services which needed addressing.

The professionalised nature of user involvement practices as enacted within the TSSP further inhibited a transformation of patient and professional roles. User involvement as implemented in this setting further served to reinforce professional hierarchies within health service organisation. TSSP professionals responsible for, and most engaged in, user involvement activities tended to be from the social care and voluntary sectors or lower down the hierarchy of the organisation, such as administrators or lower grade managers. Fewer health care professionals participated in user involvement activities and those who did tended to be therapists and nurses. Thus, user involvement activities tended to be most prevalent in the non-clinical domains of service improvement.

User involvement activities had to fit within a ‘work’ environment, taking the form of established NHS work practices such as meetings and committees. This was advantageous to professionals and those stroke survivors used to meeting or committee environments, but excluded those service users who had little experience of interacting in this way.

Finally, a transformation of patient and professional roles was not a goal that stroke survivors engaged in the TSSP particularly shared. The majority of stroke survivors observed participating in the TSSP retained their patient role, deferring to professionals as the experts. The transformation of patient and professional relationships was further inhibited by stroke survivor expectations concerning a ‘sense of belonging’ or community that involvement in the TSSP might engender. A number of stroke survivors suggested that the user groups established as part of policy implementation were important for reducing the isolation they experienced as a result of their stroke. However, some stroke survivors identified the lack of community within user involvement activities as *limiting* their involvement. The experience of participating in the TSSP was compared with other experiences of ‘involvement’ such as Neighbourhood Watch Schemes, church communities and Parent Teacher Associations in schools. However, despite the NHS being important to most people in the UK, stroke survivors involved in the TSSP appeared not feel the same affinity compared to other institutions such as the Church or education. User involvement ultimately was not about creating community, but about individualised engagement between patients and professionals – an extension of policies such as patient centred care where the patient is expected to take responsibility for their health and the management of it.

In the next chapter I explore how a similar policy of user involvement was implemented but this time in a health research setting.

Chapter 7: The enactment of user involvement policy in an academic research organisation

Just as patient involvement is a policy requirement for those working in the NHS (as discussed in Chapter 6), researchers, both internationally and in the UK, are now expected and encouraged to involve patients as 'partners' in research, rather than as mere subjects (National Institutes of Health 2012;World Health Organisation 2004). Proponents of user involvement propose that implementation of the policy will: improve research quality and research governance (Department of Health (Research and Development Directorate) 2006), thereby producing research that will meet the needs of patients and will be more likely to be implemented (Involve 2007;National Institute for Health Research 2012); democratise science and open up once private spheres of public life to give patients and the public the means to participate in research that is largely publicly funded (Beresford 2002, Caron-Flinterman *et al.* 2005;Hanley *et al.* 2003); and challenge traditional roles of, and relationships between, patients and professionals (Oliver 1997;Sweeny *et al.* 2009).

Sweeny *et al.* (2009), coming from a background as users of mental health services, argue that only those with insider knowledge and experience of a condition have the right to represent those with the condition. Ingstad (2007), a medical anthropologist researching disability, observed AIDS and gay activists making this point at the American Anthropological Association's 1992 Conference by demonstrating with signs saying '*These Natives Can Speak for Themselves',* a message which people with disabilities in developed countries have similarly advocated (Ingstad 2007, p.254). These examples, from different health fields, hint at wider questions of the relationship between the observer and the observed in all scientific research fields, including anthropology. The relationship is assumed to be one of subordination of the observed by the observer. Through the enactment of user involvement activities, user involvement policy seeks to transform this relationship.

Oliver, a non-disabled disability researcher, advocates emancipatory research, a research paradigm which changes the social relations of research production, placing 'control in the hands of the researched, not the researcher' (Oliver 1997: 18). Emancipatory research challenges the interactive process between researchers, research activity and research subjects. Oliver situates the origins of emancipatory research with the rejection of the pursuit of knowledge through both positivist and interpretivist approaches. Whilst the interpretivist approach takes seriously the definitions and perspectives of the researched, if there is no link to policy-making structures there is likely to be little influence on outcomes and changes in power relations, leaving the researched (in Oliver's example, disabled people) in the same position as they were at the outset. Emancipatory research therefore is concerned with confronting oppression based on three fundamental principles: reciprocity, gain and empowerment (Oliver 1997). Whilst much of the user involvement policy literature draws on the arguments raised by disability researchers, Oliver's argument differs in that he argues that emancipatory research is not about *empowering people* as they have to make the decision to *empower themselves*. Once this decision has been made, the role of the researcher is to facilitate the process by offering their knowledge and skills to research subjects to do with what they will.

The ‘power’ that authors such as Oliver and Sweeny *et al.* refer to is one which is held by professional researchers and exercised over people with mental health problems or disabilities. Like the analysis of power in the disability and mental health literature, the authors of policy documents promoting user involvement conceptualise power as an entity that can be transferred from one group to another. Lukes (2005) provides an alternative way of thinking about power, which has a number of dimensions: power may be concerned with securing compliance and consent through domination, perhaps through avoiding conflict; it can be hidden, unobservable; a reputation for power may be more important than whether power is used or not; or power may not even need to be exercised in order to make one group act against their own interests (Lukes 2005). As Shore and Wright (1997) have argued, an anthropological analysis of policy will ask questions such as how do policies construct their subjects as objects of power and what new kinds of identity are created through a policy (Shore & Wright 1997)?

As with the previous chapter, the central focus of this chapter is an examination of a national policy, as enacted at the local level by the Stroke Research Programme (SRP). At an empirical level, I explore how the policy to involve patients in research was interpreted and implemented within an academic research team, and to elucidate the factors which may have influenced how user involvement was put into practice. Theoretically, this chapter asks what forms of lay-expert relationships emerge as a result of implementing user involvement policy and how this affects the social relations of research production and implementation. Through describing how user involvement was interpreted and implemented in the SRP, I will argue that the policy to involve patients in research was implemented to meet research governance requirements and as part of a research endeavour, despite being critiqued by SRP researchers on a number of accounts. However, implementation of user involvement policy did little to challenge and transform the social relations of research production.

The chapter is in three parts. First, I describe how academics and researchers responded to user involvement policy. I contrast the different approach taken by professionals in the SRP with that of professionals in the Transforming Stroke Services Project (TSSP), as described in the previous chapter. Second, I consider user involvement practices: how stroke survivors were involved in stroke research beyond their roles as ‘passive’ participants in the South London Stroke Register (SLSR). Third, I focus on one of the policy aims of user involvement: the democratisation of scientific knowledge and questions concerning who has ‘control’ of the processes of research knowledge production. I argue that whilst ultimately researchers controlled this process, this aim of user involvement policy may be hard to achieve due to divergent patient and professional meanings of ‘research’ and ‘involvement’.

7.1. Responding to user involvement policy

In contrast to user involvement in the TSSP there were no documents specifically referring to the involvement of stroke survivors in the SRP. There was no written statement indicating which aspects of stroke research stroke survivors should be involved in. How stroke survivors would be involved in the SRP and what this involvement would entail was something that the Principal Investigator (PI) and I had to establish by reviewing the requirements of the policy and the literature describing previous researchers' forays into user involvement, and discussing how to involve stroke survivors in stroke research with our colleagues.

I started by reviewing policy documents and journal publications on user involvement to find out how other researchers had involved service users in their research. 'User involvement' primarily seemed to consist of recruiting service users to an advisory or reference group known as a 'user group' attached to a specific research project for the duration of the project (for example see Ross *et al.* 2005). These 'user groups' would meet a handful of times over the course of the research project. User group members would be asked to monitor the progress of the research project, and provide input into the research process, for example by helping to: draft the research questions; write the research documentation and ethics applications; and collect, analyse and interpret the data. At the time of establishing user involvement in the SRP there were few examples in the published literature of on-going ‘user groups’ attached to a programme of research rather than a single research project[30].

I wanted to establish my colleagues’ interpretation of the policy and how they felt stroke survivors should be involved in their research. So, early on in my fieldwork, I conducted a mini-survey with stroke researchers asking them about the policy of user involvement: what they understood by the policy and its relevance to their work. Whilst most of the SRP researchers could refer to the moral and ethical aims, and the research governance requirements, of the policy, researchers, particularly those from the more quantitatively focused disciplines, found it hard to see the relevance of user involvement to their work or how they could actively involve stroke survivors in their research. In an interview study on health researchers’ attitudes to user involvement Thompson *et al.* (2009) drew similar conclusions: that the key driver for researchers to undertake user involvement was to meet research governance requirements as opposed to sharing a belief in the philosophy behind the policy.

Whilst no one was critical of the policy in their responses to the mini-survey or during the interviews I conducted with researchers towards the end of my fieldwork, in other contexts (a team meeting, a chat during morning coffee) researchers within the SRP, and the wider research division, spoke critically of the policy. In the age of evidence-based medicine (Berkwits 1998) the fact that a policy promoting patient involvement

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[30] The exceptions were the Service User Research Enterprise at the Institute of Psychiatry, King’s College London and the Diabetes Research and Education User Group at Warwick University.

in research was based on assumptions, with no clear evidence to back claims that involvement leads to improved research quality and implementation, was a source of annoyance and a justification for some researchers for not ‘doing user involvement’. As I embarked on my research, I had a number of conversations with researchers from other universities who expressed surprise that in our department we were actually trying to implement the policy. This made me wonder why we were concerned with implementation of the policy if other researchers were not. These researchers appeared to have little concern that *not* implementing the policy would have an impact on their ability to meet research governance and research funding requirements.

As part of the process to identify how to implement user involvement, the PI and I held a meeting with the Register fieldworkers and researchers to garner their views on involving the Register participants in the work of the SRP. Conscious that implementing user involvement may create ‘extra work’ for these researchers, the PI and I provided a buffet lunch for those attending the meeting as a ‘sweetener’.

Once lunch had been eaten we began to discuss how stroke survivors could be involved in the work of the SRP. The Register Coordinator asked what the purpose of involvement was and suggested we needed to clarify what we expected stroke survivors to do. I put forward a suggestion: ‘perhaps stroke survivors could help to identify the kinds of questions the register asks?’ (It was common knowledge amongst those collecting data for the SLSR that Register participants found the follow up questionnaire too long and not all the questions relevant to their experience of having a stroke). Fieldworkers and researchers hesitated to respond to my question during the meeting, but a day or two after the meeting I received separate emails from three researchers raising more explicitly their concerns about asking stroke survivors to define the kinds of questions the Register asks. They felt that this may not be feasible due to the standardised nature of most of the questions and the need to keep these questions consistent each year to allow for comparison of patient outcomes over time (see Chapter 5, section 5.3 for a description of the kinds of questions The Register asks). There was an assumption that stroke survivors would not understand epidemiological research and the need to adhere to proper research practices. One researcher, a health economist who had little, if any, contact with stroke patients, primarily using data collected by the Register team for his research, was particularly concerned that having an illness or condition limited one's ability to generate unbiased questions. His view contrasts with the policy claim and view of proponents of involvement, such as Involve, that drawing on patient experiential knowledge will improve research. Criticism of 'user involvement in research' from within the SRP therefore centred on patients' lack of scientific knowledge and their inability to be objective in the identification of research questions, and the lack of evidence to support certain claims inherent in the policy.

This openly critical response to the policy was in contrast to professionals on the TSSP who rarely critiqued the policy, publicly or privately. Rather TSSP professionals regarded the policy of user involvement in the same way as other policies, such as patient centred care (Department of Health 2005a), that they are charged with implementing. Frank (2010) draws on Weber's notion of *routinization* to explain the popularity for patient centred care (PCC) in health care practice worldwide. Briefly, PCC has been defined variously and can mean increased patient input into treatment decisions, or health care professionals taking a more holistic approach to patients rather than medicine reducing patients to a site of pathology. Frank defines routinization as the 'inexorable tendency of legal-bureaucratic organisations to reduce work processes to routines – predictable sequences of actions governed by institutional rules – so that workers have increasingly little discretion in how they do their work' (2010: 1454). Frank further argues that routinization is a tendency of expert and professional systems generally, not one limited to legal-bureaucratic systems. In the TSSP, professionals' response to user involvement could certainly be described as a routinized response. However, in the SRP the response could not be so clearly defined: open criticism of the policy existed alongside a need to demonstrate compliance with the policy to meet research governance requirements.

So far then in this chapter, I have shown that the policy was criticised by SRP researchers on a number of accounts: the limited evidence base for the policy claims; little assurance between practice of the policy and an increase in the success rates of funding applications; and reservations from some researchers of the ability of stroke survivors to generate 'objective' research questions. However, despite these criticisms it was clear that some form of involvement had to be seen to be practised, if not to meet research governance requirements then to meet the aims of the research project through which I was employed (see Chapter 1) and report achievements and milestones to the study funders. Furthermore, as I discussed in Chapter 5 (see section 5.4) enacting user involvement and evaluating the process and outcomes ethnographically would benefit the SRP, through a research endeavour, generating publications providing a critical analysis of user involvement policy.

Based on the existing literature on user involvement, guidance from organisations promoting user involvement, such as Involve, and discussions with researchers in the SRP, the PI and I decided to adopt a ‘user group’ format to implement user involvement. We planned to hold an introductory meeting with SLSR participants to discuss options for researchers and stroke survivors to work together. Our hope was that there would be enough interest from stroke survivors to set up a ‘user group’ which would meet regularly to focus on a range of research projects within the SRP as opposed to a user group attached to a specific, time-limited research project. The next section describes the process of inviting SLSR participants to participate in the work of the SRP and undertaking research-related user involvement activities.

7.2. Implementing user involvement in stroke research

In the previous chapter, I argued that the professionalised natured within which user involvement-related activities were conducted meant that TSSP professionals had to actively encourage stroke survivors’ participation. Stroke survivors with appropriate skills to be involved (e.g. meeting and committee experience, articulate, vocal) were particularly sought to ensure the success of the user involvement project. In the case of user involvement in the SRP, the PI and I wanted to avoid ‘proto-professionalism’ where certain types of patients (those deemed ‘appropriate’ for user involvement) are selected by professionals to be involved in research (Caron-Flinterman 2005). Perhaps in keeping with the epidemiological background of the Register, a systematic and ‘democratic’ approach was adopted to invite SLSR participants to an introductory meeting to explore ways in which they could work together with stroke researchers. Although the PI and I recognised that those choosing to attend the meeting would be a self-selecting group, we hoped that our method for inviting SLSR participants would give everyone who wanted to, the opportunity to participate.

Next I describe the approach we took to invite Register participants to participate in the work of the SRP, the space where user involvement activities took place, the meetings within which user involvement activities were conducted, and the Register participants and stroke researchers who participated in user involvement activities.

Inviting stroke survivors

Whilst we had established researchers’ views on implementing user involvement policy we had not as yet engaged with stroke survivors themselves. The PI and I decided that an introductory meeting with interested Register participants would give us an indication of the level of interest stroke survivors had in participating in the work of the SRP. We asked fieldworkers to invite stroke survivors to an introductory meeting from an epidemiological pool, that is the SLSR. Over a two month period prior to the introductory meeting fieldworkers visited 64 SLSR participants to complete the routine follow up questionnaire. These participants had had their stroke from three months to ten years prior to the follow up appointment. Once the follow up questionnaire had been completed the fieldworker invited the participant to attend the introductory meeting and handed the participant an invitation (see Appendix IX). The stroke medical consultant and stroke specialist nurse from a local stroke unit were asked to mention the group to patients whom they saw in clinic and invite them to participate.

Despite our aim of being inclusive, fieldworkers and researchers working on the Register sent invitations to six SLSR participants who they thought would be ‘good’ for the group. A couple of days after our lunch meeting, Isla, one of the fieldworkers on the register, told me of someone on the register who she would send an invite to as they may be interested in attending the group. During the follow up interview this person always showed an interest in the research the SRP was undertaking or an awareness of research in general, thus Isla thought they may be interested in a group whose purpose was to discuss stroke research. Then I received emails from the other fieldworkers letting me know about additional register participants who they had invited to the introductory meeting. On asking why they had selected these Register participants, I was told that these were people who, during the follow up interview, discussed with the fieldworker ways to improve stroke prevention and communication with General Practitioners (GPs); expressed an interest in joining a group or meeting others and getting out of the house; were keen on finding ways to complete their recovery from stroke and to improve the lives of other people in the same situation; and were compliant with the research process (e.g. made themselves available for follow up interviews, and did not resist answering questions and giving information to fieldworkers or researchers).

The invitation asked Register participants to complete and return a reply slip stating their interest or not in attending the introductory meeting. Nine people replied with their intention to attend the meeting, one of whom required disabled access as their stroke had restricted him to a wheelchair. My next task therefore was to find a suitable place to bring stroke survivors and researchers together to ‘do’ user involvement.

Finding a space for user involvement

As described in Chapter 5, the building where the SRP was housed was inaccessible for people in a wheelchair (see Chapter 5, section 5.3). We were therefore unable to hold user group meetings in the same ‘space’ where research was conducted and discussed by researchers. I had to locate a wheelchair accessible meeting room in another part of the university campus. I contacted the university’s disability officer. However, my request for help to find an accessible meeting room for a research-related activity stumped the disability officer - her main role being to ensure disabled students have access to the university buildings such as libraries and lecture theatres. In seeking out an accessible meeting space it was apparent that certain categories of people connected to the university were afforded greater priority. The university as an education institution had to ensure disabled students were included, but as a research institution the needs of disabled researchers or research participants seemed less pressing. The apparently simple exercise of locating an accessible space to meet highlights the institutional and organisational barriers to implementing user involvement policy.

I was aware of a Boardroom in the University Theatre, conveniently located across the road from the SRP offices. Although the room was not ideal, being on the ground floor made it accessible for those members in wheelchairs. Once inside the theatre the meeting room itself was reached through a series of heavy wooden double doors, requiring at least two people to hold open the doors to allow those in a wheelchair to access the room. The room was painted in the usual institutional shade of magnolia, the paint work becoming shabbier and dirtier over time. It had little natural light and poor electrical lighting, adding to the gloomy atmosphere, and was dominated by a large, heavy, boardroom style wooden table. During the period of observation the room fell into an increasingly poorer state of decor and took on an additional role as a store room for theatre props.

The first meeting between SLSR participants and researchers was held in this room and was attended by eight stroke survivors and the wife of one of the stroke survivors. Professor Brooks, the Head of the SRP, formally opened the meeting, emphasising the importance of stroke survivors' input into research. The stroke survivors listened intently in silence as Professor Brooks explained that currently most of the work of the SRP is 'one way', with researchers asking questions of people who have had a stroke. Professor Brooks hailed the meeting as a start of a partnership between researchers and stroke survivors 'teasing out what we should be doing to increase input from people who have had a stroke and their friends and relatives.' After his welcome speech, Professor Brooks apologised for having to immediately leave due to other work commitments. ‘Well I think you should stay’, bellowed Pauline, we need the ‘top people’ here. An awkward silence ensued with the Professor apologising once more for having to leave before making his exit. Pauline continued to express her dissatisfaction at the Professor’s absence. The PI quickly interjected and suggested that we start to discuss stroke research and how we could work together.

The PI and I and those stroke survivors attending the first meeting agreed there was value in continuing to meet on a regular basis. Thirteen other stroke survivors had asked to be kept informed of the meeting outcome as they were not able to make the date of the first meeting. Through anonymous, postal voting group members determined how often and when the group would meet, and the name for the group: the Stroke Research Patients and Family Group, hereafter referred to as the SRPFG. ‘Doing user involvement’ therefore entailed inviting stroke survivors from the SLSR and conducting research-related activities within the format and structure of a ‘meeting’, which I describe below, using a vignette from the fieldwork.

SRPFG meetings

It was just after two o’ clock on a Tuesday afternoon. Seven stroke survivors sat around a large wooden table along with the PI, Lucy, a stroke researcher, and me. At one end of the table a laptop and projector were set up, beaming a PowerPoint presentation with the agenda for the meeting onto a large white screen at one end of the room. The meeting began with discussion of the first agenda item of the meeting - the first draft of *Forward*- a research newsletter to inform Register participants of the results of stroke research[31]. The PI handed out the draft copies of the newsletter while I explained that we would like people's comments on the draft – the content of the stories, the size of the text, whether the newsletter was easy to read or overwhelming because there was too much text. While we were discussing the layout of the newsletter Michael, a stroke survivor in his early 50s arrived. It was the first meeting he had attended and I was quite surprised to see him because as he worked during the day it was hard for him to attend the meetings held during work hours. Betsy arrived soon after. Betsy was one of the oldest stroke survivors attending the meeting and had problems with walking due to a wound on her leg that was refusing to heal. She came to the meetings by a taxi that we had organised for her. Betsy apologised for being late and said that her taxi driver did not know his way to the meeting venue and had got lost. While I made a cup of tea for Michael and Betsy, the PI continued to discuss the newsletter with the rest of the group.

'What sort of things would you like to see in the newsletter', he asked. Pauline said that she would like to see some things on healthy living such as menus for healthy eating and recipe suggestions. Others agreed adding that it would be good to have some advice from a dietician. The general consensus was that the newsletter should contain tips on leading a healthy lifestyle – exercise and positive actions that could be taken to prevent further strokes. Pauline continued to offer suggestions for the

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[3131] See Appendix XII for a copy of the first issue of Forward newsletter.

newsletter. ‘We’ve got to do more on people leaving hospital. It’s essential and you’ve only got a paragraph on it’ she said referring to the back page of the newsletter where there was a short article on the results of ‘The Early Discharge Study’, a study to help stroke patients leave the stroke unit earlier than normal with the support of a team of therapists to provide rehabilitation at home. ‘Funnily enough’, the PI said, today Lucy will be giving us a talk about that very topic. The PI introduced Lucy as a member of the research team and explained that she had started out working on the Register, interviewing people, but was now starting to work on a new project looking at what stroke services are provided once someone leaves hospital. Pauline said ‘if we do this together, these stories, once we get going, we’ll help a lot of people.’

Lucy stood up and moved towards the end of the table near the laptop. While I loaded her presentation, Lucy thanked the group for inviting her to come and speak and that it was a very exciting opportunity for her to come and talk about this new project. The PI, interjected and asked Lucy if people were allowed to ask questions. Lucy replied saying that people should ‘ask questions along the way rather than saving them up for the end’. Lucy added that this was the first time in the Stroke Research Programme that stroke survivors will have contributed to the design of a new study.

Lucy asked if anyone ‘had been on a stroke unit’. Most people shook their heads. ‘What do you mean by a stroke unit?’ asked Pauline. ‘There isn’t actually a definition’, replied Lucy, ‘but there are a few things which they tend to have in common.’ Lucy explained in detail about what stroke units are like, including details such as the team meeting and the multidisciplinary nature of stroke teams and the fact that people from different disciplines talk to each other, which is quite unusual in a hospital ward. Michael said ‘Of course all the other wards, they’d be dealing with all other things whereas a stroke unit is just stroke’. Lucy agreed and said a stroke unit is just stroke, very specific. Joan, who was one of the first stroke survivors to participate in the Register having had her stroke over ten years ago, said that she was on a general medical ward when she had her stroke. Pauline asked about the equipment on the ward and whether this equipment was available at home. Lucy said that stroke units, because they are specialised in stroke, they are more likely to have equipment you need. On a general ward health care professionals would be dealing with people with a range of illness so they might not have things specifically for stroke. Joan said that these wards didn’t have any literature either, not stroke specific literature anyway.

Moving through her presentation, Lucy told that group that they ‘may be surprised to learn that there are actually policies to say what should happen when you go home. According to these policies discharge from hospital to home should be smooth, patients should receive longer term rehabilitation and support once home and patients should have a say in planning their own discharge from hospital. ‘I wonder if you think this is actually happening?’, Lucy asked. Everyone laughed. ‘Well put it this way’, said Pauline, ‘we all want to get out earlier than we should.’ Michael nodded in agreement. William said he thought patients having a say in their own discharge was ‘highly dangerous’; people want to get out too quickly and the experts are better placed to say when someone should go home.

Roger, the husband of Marian who had had a stroke, said ‘we waited six months before we got any help’. We were told she would be housebound, he continued, referring to his wife. Marian took over the tale: ‘I kept ringing up for an appointment but all I got was the answer phone and my doctor too, she tried ringing the hospital, and when we did get an appointment, we turned up and the clinic was closed’. Marian said that she had a physiotherapist and it was the ‘physio that got me going [walking]’. ‘Wonderful people, physios’ chipped in Jim.

‘When you were discharged from hospital’, the PI asked Roger and Marian, ‘what did they tell you?’ ‘Nothing’, Marian and Roger both replied. ‘The doctor didn’t even say what kind of stroke I’d had’ continued Marian. Marian said that she got more information from their GP. Marian said that she thought they should tell you more in hospital. Lucy asked what kind of information would you have liked to know, what would you have liked to hear. Marian said she would have liked to know what kind of stroke she had. ‘Why?’ asked William abruptly, ‘what help would that have been?’ Marian explained that she had a friend who was a nurse and she had asked what kind of stroke it was and Marian ‘couldn’t tell her’.

Michael reiterated a similar tale: it was a few months before anyone contacted him after he came out of hospital about physiotherapy. Lucy continued to explain the mismatch between policy recommendations and what happens to people in reality. What I don’t understand, said Pauline, ‘is why they recommend all this, where does it all go, it flies out the window. There’s some reason why it doesn’t happen.’

Lucy asked the group what their ideal service would look like. ‘One good idea’ replied Michael, ‘would be for people to be examined on a regular basis to discover the possibility of further strokes’. The PI asked Michael if his GP could do this. Michael replied that he ‘supposed he could if I asked him’, but that he was not confident about how much his GP ‘knew about strokes really’, and there are three GPs in his local practice and he sees a different one each time. William questioned the value of a stroke check-up. William explained that his wife, who had both a stroke and diabetes, had been under regular care with her diabetes prior to her stroke. Her doctor thought she would have been the last person on her list to get a stroke. Consequently William could not see how a check-up would really help things.

As the time neared to four o’ clock and the end of the two-hour meeting, members began to lose concentration on the research discussion. Betsy, who was sitting next to the PI, was speaking intently to him making it hard for him to carry out his chairing role and keep the group focused on the task in hand. Pauline had retrieved from her bag an old fashioned balloon bicycle horn and was honking the horn whilst explaining that she took it with her to bingo in case she won any money. Lucy quipped that she was relieved that Pauline hadn't used it during her presentation, to which everyone else burst out laughing.

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This vignette describes one of the regular meetings between stroke survivors and stroke researchers. Whilst it describes a single meeting most meetings were similar in that there was lively, light hearted discussion; experiences of stroke, the NHS and living in Lambeth and Southwark were made public and shared, and the focus often strayed away from research despite concerns to improve the quality of NHS care. Meetings were held throughout the year, every six weeks, lasting for two hours in the afternoon, although for the PI and I, as organisers of the meeting, preparation for the meeting would take up a good part of the week prior to the meeting, most of the day of the meeting, and a good few hours after it.

In the week prior to the meeting I called all the group members to remind them of the meeting and arranged taxis for those who could not use public transport due to mobility problems caused by the stroke or other co-morbidities. The PI and I would spend time planning the research-related activities we intended to discuss with the group. If another researcher was to present their research to the group then time would need to be spent with them ensuring their presentation was free of research jargon and that they were aware of the level they needed to pitch their presentation.

On the morning of the meeting I would make any last minute reminder telephone calls to SRPFG members, finish off the power point presentation and start to gather together all the equipment and refreshments we would need for the meeting. For our first meeting the university catering service provided tea and coffee, but this generated complaints from group members about the disgusting coffee, and for the SRP, an extortionate bill. Conscious of the costs of ‘doing’ user involvement given the lack of evidence for user involvement[32], the PI and I decided from the second meeting on to organise our own refreshments; this involved buying our own kettle and cups, and on the day of the meeting, biscuits. In the tradition of a typical English meeting, and to show appreciation of Register participants for their attendance, I bought biscuits from one of the pricier supermarkets. A couple of meetings later I was chastised by one of the members, Catharine, for providing unhealthy biscuits and potentially contributing to members having a second stroke. Catharine was a former teacher in her 70s. She said she felt lucky to have escaped a more serious stroke and consequently was concerned with looking after her health through diet and exercise - doing what she could to prevent a further stroke. Following Catharine's preference for healthy food to be provided, the group agreed that biscuits would no longer be supplied and we would settle instead for fresh fruit and nuts.

Half an hour before the meeting was due to start, the PI and I would make our way over to the University Theatre carrying a kettle, a box with 20 cups and tea making things (teabags, coffee, sugar, milk), bags of fresh fruit and nuts, a folder containing the hand-outs for the meeting, a memory stick with the PowerPoint presentation stored on it, and a mobile phone to call late arriving taxis. On arrival at the Theatre we would stick up notices on the doors to direct stroke survivors to the meeting location

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[32] Whilst the Department of Health policy requires researchers to involve patients in research and funds an organisation, Involve, to promote user involvement in research, there is little funding at the local level for researchers to implement user involvement. User involvement activities are expected to be factored into and funded through research grants.

in the Boardroom, rearrange the furniture so that the seats were place around the large wooden table with spaces left for those using wheelchairs, load up the PowerPoint presentations onto the laptop and start up the projector. We would bring to the meetings nervousness and a sense of trepidation wondering whether the taxis would arrive on time, how many people would attend the meeting, and how would those attending respond to the activities we had planned. Whilst one of us would get the kettle on for tea as group members began to arrive, the other would hover outside the theatre, waiting for those members arriving by taxi and begin the task of helping people out of the taxis and through the heavy wooden doors that led to the Boardroom.

Once most of those who were expected to attend the meeting had arrived and tea had been made, the meeting would start. The meetings immediately took on a fairly formal structure adhering to the conventions of a 'meeting' with a set agenda, introductions and apologies and formal recording of the meeting through the taking of minutes. The PI and I would begin the meeting by welcoming everyone, giving apologies on behalf of those who could not attend and welcoming any new members, stroke researchers or external visitors. We would then focus on the two or three 'activities' related to stroke research which the PI and I had planned prior to the meeting.

Involvement in 'research' took a number of forms: discussion of stroke policy documents and responding to Department of Health (DoH) consultations; discussion of research projects at varying stages of the research process with stroke researchers;

commenting on how to improve research practices such as patient consent forms for the Register; undertaking a pilot study to investigate a question generated by one of the group members; and writing a research newsletter for Register participants. The wide variety of activities the group undertook, some not immediately appearing to be related to stroke research, were a consequence of not always having enough research business to fill each two hour meeting.

In terms of user involvement policy the research activity which most clearly required researchers to provide evidence of user involvement activities is the writing of the research grant application. As outlined in Chapter 1 (see Figure 1.2, section 1.3) nearly all research grant applications, whether they originate from the DoH, a research council or a medical charity, require researchers to state how service users were involved in the writing of the research grant application and how service users will be involved in the research should it receive funding. To meet research governance requirements and to demonstrate user involvement some stroke survivors commented on research grant applications outside of the scheduled meetings. On one occasion a senior researcher on a grant application thought it would be useful to include a lay collaborator alongside research collaborators and investigators. Catharine was invited to contribute to the application a couple of days before the application deadline to comment on the research questions. The PI and I sat with Catharine and went through the objectives and aims of the research proposal and asked Catharine for her comments. Catharine replied saying that she thought it all sounded ‘very good’ and seemed like the ‘right thing to be doing’. However, she said that the ‘short notice’ made it difficult for her to ‘comment usefully’ as it was hard to take it all in. Not all research grants submitted to funding bodies could be discussed and commented on by the group during the meetings. A researcher interviewed commented that user involvement becomes another factor ‘to fit it into your research schedule ... [timings are] quite tight anyway and ... research doesn’t actually always work to plan’ making it hard to fit user involvement into the study.

Although the SRPFG met regularly, user involvement was physically and temporally separated from the SRP. The group met away from the arena where researchers conducted research and made decisions, and research timetables and pressures to meet funding deadlines did not always fit with scheduled SRPFG meetings meaning that only certain research studies within the SRP were discussed with stroke survivors.

Stroke survivor involvement

Over the three years of data collection membership of the SRPFG increased to 41 stroke survivors and carers through SLSR fieldworker contacts, adverts in the SLSR newsletter, and contacts with local voluntary organisations. The type of membership varied (see Table 7.1). Eleven members never physically attended a meeting, but had requested to be kept informed of the group through meeting minutes. On occasions one or two of these ‘postal members’ contributed to group tasks (such as commenting on a research proposal) by post. Eight ‘occasional members’ attended one or two meetings before deciding not to participate further. An active core of 22 ‘regular members’ attended frequently. Throughout the course of the three years of data collection an average of 11 members attended the six-weekly meetings.

Table 7.1 Characteristics of group members

	Regular members n=22	Occasional members n=8	Postal members n=11
Stroke survivor/carer	3 carers, 19 stroke survivors*	2 carers, 6 stroke survivors	1 carer, 10 stroke survivors
Time since stroke at joining group	(6 months – 10 years)	(2 months - 2 years)	(3 months – 5 years)
Gender	12 male, 10 female	3 male, 5 female	5 male, 6 female
Age range	55-86 years	42 – 81 years	42 – 91 years
Post-stroke disability	1 person with aphasia, 4 wheelchair users, 3 requiring support with walking	No physical disabilities	Not known

*One ‘regular’ member, Betsy, told me during an interview that she had not actually had a stroke despite continuing to complete follow up questionnaires for the SLSR.

These participants were demographically fairly representative of stroke survivors in the two boroughs. In terms of ethnicity, most of the regular members were white having been born in Britain, with one person originating from India, one from Africa, two from the Caribbean and one from Eastern Europe. Regular group members were representative of the stroke population regarding social background as defined by occupation. Occupations prior to the stroke or retirement ranged from cleaner, telephone engineer and mechanic, to teacher, vicar and naval officer. A considerable number of people with serious disability caused by the stroke participated in the group, in contrast to assumptions in user involvement guidance that disabled people are likely to be excluded from involvement activities (Hanley & Staley 2005).

Whilst there was variation within the group in terms of members' ethnicity, social background and post stroke disability, what united the group was the civic duties group members undertook voluntarily. With the exception of one or two members, most members had been active in the local community prior to becoming involved in the SRP. Jim (who I first introduced in Chapter 6) described his stroke as severe as he was hospitalised and in a coma for a long time, followed by months confined to a wheelchair unable to walk. During an interview with me, Jim described himself as 'lucky'. He had recovered well from his stroke once he had met with a physiotherapist 'convinced that he could get [Jim] walking'. Now back to almost full mobility, Jim volunteered for numerous organisations, including being a school governor and helping out with pupils' reading at a local primary school, and being an active member of his local church. Whilst practicing walking along his local streets with his physiotherapist, Jim learnt of a community 'safer streets' campaign. Jim decided to volunteer for that as well since he 'might as well do something useful' whilst learning to walk again. Joan had previously been a nurse and was one of the first stroke survivors to participate in the South London Stroke Register having had her stroke over ten years prior to joining the SRPFG. Since her stroke and retirement Joan volunteered in the local hospital and helped run the local stroke club. Prior to her stroke Catharine had volunteered with the Alzheimer's Association. After what she describes as a mild stroke, Catharine remained an active participant in lifelong education. Likewise, Lily, who had had three strokes, was concerned with her diet and remaining as active as possible. Lily was a volunteer at the local branch of Help the Aged and active in her local church.

Even those who were not currently active within a formal voluntary organisation were regular letter writers to their local MP or councillor, or attended community meetings on local issues. Despite Betsy's limited mobility and the fact that she rarely left the house, she could engage politically with the external world through letter writing. During SRPFG meetings Betsy was one of the quieter members appearing to have little to say about her stroke (perhaps because she believed she had not had a stroke) but was more talkative during one-to-one conversations with me. During the period of fieldwork I got to know Betsy quite well. I only visited her house once but would see her at meetings and have regular, lengthy telephone conversations with her. Betsy rarely left her house – attendance at the SRPFG meetings being one of her few regular outings. A neighbour did her shopping for her and the district nurse would visit Betsy to attend to the wound on her leg. The one occasion I did visit Betsy was to carry out an interview with Betsy about her time in, and experience of, the SRPFG. I sensed that my visit was a big occasion for Betsy. This was one of the longer interviews I had conducted and I was probably at Betsy's house for a good three hours. First Betsy proudly showed me round her house. She had gone to a lot of trouble to put on a proper English afternoon tea, asking her neighbour, who did her shopping for her, to add cakes and biscuits to the usual weekly shop[33].

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[33] As someone with Coeliac Disease (an autoimmune disorder of the small intestine, treatable by following a gluten-free diet) I should not have really eaten the spread that Betsy had laid out, but seeing the effort she had gone to I felt to refuse to eat the sandwiches and cakes would have been rude. I felt some anxiety over the need to 'reciprocate' and that to decline the food would be would be to reject Betsy's 'gift' of thanks for helping her get to the meetings (Betsy was always so grateful to us for

During the interview we often digressed from the interview questions as Betsy showed me the brochures for some sheltered accommodation a distant relative wanted her to move into, or Betsy's handyman popped by to discuss jobs which needed doing round the house. We talked about political engagement and she described herself as 'politically minded'. She told me how she loved to watch the political programmes and when she had ideas (such as a convalescence home for stroke victims by the seaside) she had a 'good mind to write to Gordon Brown about that, or Tony Blair… But you've got to know who to write to. Somebody that will understand. …And has got the powers, yes, to bring it into action, bring it up in parliament.' Betsy commented that her own MP, Harriet Harman, was someone who would act on people's concerns and she had 'been in touch with her with various things'.

A number of authors have argued that government policies are often about creating new forms of citizens, those with a sense of civic responsibility (Barnes & Prior 2009;Cowden & Singh 2007;Shore & Wright 1997). Similarly, exploring user involvement policy through the lens of biosociality or biological citizenship suggests that policy or new practices of science and medicine will engender on the part of citizens a sense of identity and citizenship based on biological and health responsibility (Rabinow 2008;Rose & Novas 2005). In this setting however, I observed that the policy

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providing her with a taxi to the meetings). I felt that my visit to Betsy's to do an interview was like a social occasion for her; in return for agreeing to take part in an interview I would have afternoon tea with Betsy. I felt I had to partake in the afternoon tea in order to fulfil my end of the bargain. I have heard from other stroke researchers of similar afternoon tea situations arising when they visit a research participant to undertake an interview.

was not creating subjects with a sense of civic responsibility and duty as those participating in the group had already acquired this identity. Many group members had also acquired, prior to coming to the group, a sense of health responsibility, or biological citizenship (Rose 2007) as a consequence of having a stroke, modifying their diets and behaviour, seeking out information in order to prevent a further stroke.

During the process of inviting SLSR participants to the introductory meeting I telephoned 44 of the 64 invitees who had not returned the reply slip to see if they planned to attend the meeting or not. A common reason people gave for not participating was not being able to leave the house or travel alone due to illness or disability relating to the stroke and other co-morbidities. There were a considerable number of people who felt that the meeting did not warrant their attention; either the effects of their stroke had not been that bad so the meeting was not particularly relevant to them; or they felt that they would not have much to offer. In a few cases, people told me that the stroke was not something they wanted to think about or focus on – instead preferring to get on with their lives.

Doyle and Timonen (2010) found similar attitudes to participation in their community-based participatory research study investigating social care and support services for older people. In this study the authors had defined the community from which to draw older people to be involved in the research by geographical location and age. However, many of the potential participants who fulfilled the age and location criteria believed that the research was not applicable to them as they were not in need of additional support or were content with their current levels of social participation. Instead, they believed that the research was more applicable and beneficial to socially isolated and marginalized older people. This led the authors to reflect on whether they should have limited the target population or the community under study to those who could be characterized as socially isolated, disempowered, and in receipt of inadequate services (Doyle & Timonen 2010). What may be of more relevance is how the policy is 'subverted' (Barnes & Prior 2009). User involvement policy overlooks that some patients may not wish to identify with or be defined by a particular illness or condition. It could be argued that the policy 'fails' to be implemented due to the large number of stroke survivors on the SLSR who chose *not* to participate in the user involvement activities. This theme will be developed further in Chapter 8.

Researcher involvement

Over the course of my fieldwork ten other researchers from the SRP participated in meetings – usually to present and discuss with group members the particular research project they were working on or responsible for. As Table 7.2, overleaf, illustrates researchers with a social science background were more likely to attend the meetings to actively involve stroke survivors in their research than researchers from a clinical or quantitative background, and more female researchers took part in the user group than male researchers.

The dominance of social scientist researchers may reflect a tendency for the PI and I (social scientists by background) to rope in our closest colleagues to present at the SRPFG, and a presumed association of social science research with user involvement in research, which I discuss below.

Table 7.2 Researchers participating in the SRPFG

Researcher characteristics	Number of researchers (n=14)
Research discipline	
Epidemiology (clinical)	1
Health psychology	1
Social science	7
Register co-ordinator (clinical)	1
Fieldwork/data collection	3
Public Health Medicine	1
Research level	
Principal Investigator	2
Post doc	1
Research Associate/Assistant	10
Medical student	1
Gender	
Female	11
Male	3

Early on in my fieldwork, I was discussing my work with a health economist, Derin, from the SRP. Derin told me that he was glad that his ‘research would never need to involve service users.’ This sentiment, that certain research disciplines are suited to involvement, is further echoed by research on the impact of involvement in research undertaken by Involve. Their report on the impact of public involvement in NHS, public health and social care research acknowledged the value of public involvement to clinical trials research, but noted that public involvement was of ‘particular value in qualitative research where participants are asked to share their views and experiences’ (Staley 2009). This leads to an interpretation of user involvement in research that it is akin to qualitative research, and perhaps a misunderstanding about the nature of qualitative health research - that it is solely about understanding patients’ views and experiences.

Although user involvement may have rhetorical importance through the policy requirements, in practice it is associated with and implemented by the less 'scientific' disciplines[34]. Thompson *et al.* (2009), in their study of health researchers' attitudes to user involvement, concluded that different types of researchers had differing responses to user involvement. Qualitative researchers spoke of the ethical and moral reasons for user involvement whereas researchers from a biomedical background defined user involvement along lines of public understanding of science – user involvement being a mechanism to educate the public about science (Thompson *et al.* 2009).

One criticism researchers have levelled at the requirements to undertake user involvement is that it is not valued in the academic setting where obtaining research grants and publishing papers takes precedence (Thompson *et al.* 2009). Zoë, a researcher who presented some of her doctoral research to the SRPFG questioned, during an interview with me, whether 'you get respect from your colleagues for having done [user involvement], or do they think you're a bit of a fool for wasting your time doing it?' In 2006 the Royal Society, UK Research Councils and Wellcome Trust published a report on researcher attitudes to public engagement in science and similarly found that while researchers recognised the importance of engagement, their priority was to publish and obtain funding. Respondents reported that public

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[34] In health research qualitative research ranks less highly than research using quantitative methods, the former criticised for lacking scientific rigour (Mays & Pope 1995).

engagement activities were seen by colleagues as being bad for their careers, carried out by those who were 'not good enough' for an academic career (Royal Society, RCUK, & Wellcome Trust 2006).

Decisions about implementing user involvement are determined by the context, policies and attitudes of the wider organisation within which user involvement is being implemented (Morrow *et al.* 2010). In this setting, because we could not hold user group meetings in the same space where researchers were located, the result was that user involvement was physically separated from the rest of the work of the SRP. ‘Doing’ user involvement away from the space where researchers discussed and carried out the majority of their research perhaps contributed to a perception among SRP researchers that user involvement was not their responsibility. It was rather, the responsibility of those researchers charged with the user involvement research project (i.e. me and the project PI) rather than a responsibility for the team as a whole. Towards the end of my fieldwork, through interviews with SRP researchers, I learnt that what I had sensed as a lack of interest in user involvement was rather an understandable response to user involvement as one of a number of discrete topics under investigation within the SRP. Research was conducted in the SRP by assigning junior contract researchers to a particular research question linked to specific funding, overseen by a principal investigator who often had responsibility for three or four projects simultaneously. There was little question that another researcher would take responsibility for that research, unless they were formally given responsibility to. As ‘user involvement’ was something that the PI and I were researching, user involvement was therefore something that other researchers need not be concerned with.

One of the policy aims of user involvement is to adjust the power between researchers and the researched. However, in this setting, enactment of user involvement policy highlights the power imbalances between different types of researchers. In the SRP there was a tendency for a certain category of researcher (social scientists, women) to take responsibility for enacting the policy of user involvement yet the SRP, and perhaps to some extent the wider research division, benefited by being able to demonstrate that the policy was being adhered to. One way for an academic department to ‘insidiously’ exercise power and maintain traditional hierarchies of disciplines is to rest responsibility for user involvement with a certain category of researcher whilst at the same time benefitting from the enactment of the policy (Lukes 2005).

The political importance of a policy can be seen in the way organisations promote their enactment of the policy in public documents. To be seen to be ‘doing’ user involvement is to reify user involvement into an action, activity or practice. The policy imperative to be *seen* to be ‘doing’ user involvement was made clear to me when one day I came to work to see a new poster up on a notice board promoting the work of the Research Division. This poster, outlining the working principles of the Research Division, described user involvement as ‘underpinning the work of the division’. Given that only one other research group within the Research Division, aside from the SRP, was attempting to implement user involvement this statement struck me as somewhat grandiose compared to what was actually happening. On other occasions through the course of the fieldwork I observed similar examples of research groups representing themselves as compliant with the new policy: the rhetoric of research policy incorporated into the organisation's self-presentation.

Two years into my fieldwork, after the SRPFG had been established for over a year, I was asked to present our experience of user involvement to an audience of clinicians taking part in an annual meeting of the South London Stroke Research Network. The morning session focussed on informing clinicians about new stroke trials, inviting them to recruit their patients to these studies. The afternoon session was devoted to the work of the Stroke Research Network[35], user involvement being one of the items under discussion. By the time user involvement was discussed (the last agenda item of the day) all but one of the doctors had left the meeting with only nurses remaining. Nurses, the majority of whom were female, were the professional category who remained at the meeting to discuss user involvement in the Stroke Research Network whilst the, predominantly male, doctors, with one or two exceptions, left the meeting citing other work commitments to attend to. The apparent importance of user involvement as a policy recommendation was demonstrated through its inclusion at a

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[35] The Stroke Research Network was established in 2006 to coordinate and provide infrastructure for stroke clinical research with the ultimate aim to improve quality of life, influence patient care, and save NHS resources. There are eight local research networks providing practical support for establishing and running research studies, developing local research capacity, and working to increase participation in research studies by people who have had a stroke or who are at risk of stroke.

research meeting, but its positioning towards the end of the day, with few senior researchers in attendance, reflected the low priority it was afforded.

In this section I have described at how stroke survivors were involved in the SRP through the formation of a ‘user group’ who engaged with stroke researchers during six-weekly meetings. A representative group of stroke survivors participated in the user group in terms of the stroke patient demographic. However, with the exception of one or two the majority of stroke survivors participating in the user group were engaged citizens. Therefore, in this setting user involvement policy created a new space for those already so inclined to exercise citizenship but did little to create a new kind of engaged, civic minded citizen. Over the course of my fieldwork, female researchers and researchers predominantly with a background in social sciences were more likely to attend the user group meetings than researchers from a clinical or quantitative background. These observations reflect the value and status of user involvement in biomedical research, with a tendency for user involvement to be associated with qualitative research, and public engagement activities affording low priority for career progression.

I have argued that rather than bringing together researchers and the researched, the way the policy was interpreted in the SRP served to separate user involvement from the work of the SRP. User involvement was physically and temporally separated as meetings had to be conducted away from the researcher work space and did not always fit easily with research timetables and deadlines. User involvement was restricted to certain types of research – social science research tending to be discussed with the user group. In the following section, I explore the democratisation of scientific knowledge through the research activities the user group undertook as part of implementation of user involvement policy.

7.3. Democratising scientific knowledge

One model of involving lay people in research that predates DoH user involvement is participatory research (such as community based participatory research, action research, participatory action research). Its basic premise is that research is conducted with the aim of creating knowledge to engender action and change (Israel *et al.* 1998). UK user involvement policy documents do not make such an explicit link between user involvement, research and action as participatory forms of research. Nevertheless, the researcher and the researched are reimagined as ‘partners’, and claims are made that active involvement of the researched will lead to research which is more likely to address service users’ needs and consequently is more likely to be implemented (Department of Health (Research and Development Directorate) 2006; Farrell 2004).

In this section I explore the extent to which democratising scientific knowledge through implementation of user involvement policy transformed relationships between the researched and researchers, the uses to which experiential knowledge was put and the outcome of the research endeavour. I examine these questions and the assumptions inherent within user involvement policy in light of research activities undertaken with the user group: the production of a research newsletter to disseminate results from Register research to Register participants; a user-identified research project investigating the costs of stroke to individuals who have had a stroke and their families; and presentation of research results to SRPFG members by stroke researchers. I use these examples to highlight assumptions inherent within the policy concerning: the nature of experimental or expert knowledge to inform research; patient and professional understandings of research; and patient and professional understandings of 'involvement'.

Experiential/expert knowledge to inform research

User involvement policy claims that enactment of user involvement will enable service users to identify questions based on their needs. It is suggested that the results of research based on user identified questions are then more likely to be put into practice. However the evidence for such claims is scarce. Based on observations in the SRP, I argue that whilst I observed user identified questions being pursued, the results of user defined research were not utilised to improve stroke survivors' situations. Little action was taken to transform the research knowledge created by a user defined question into action because the question did not meet researchers' ideas of what was an appropriate research question for inquiry.

For the first year of SRPFG meetings much of the research work involving stroke survivors was to design and conduct a pilot study based on an idea from two of the group members, Anthony and Carol, to look at the costs of stroke facing stroke survivors and their families. Anthony and Carol had been married for over 20 years and had two grown up children. Anthony was a vicar and Carol had been a hospital social worker. Anthony had his stroke early on in his retirement just as he was embarking on doctoral research on multi-faith groups. In terms of time since stroke, Anthony was one of the ‘newer’ stroke survivors participating in the group, having had his stroke just five months prior to the establishment of the SRPFG.

One thing which had struck Anthony and Carol, as they negotiated health and social services once Anthony had been discharged from hospital, was the length of time they had to wait for rehabilitation services to start, in the meantime having to pay for private rehabilitation therapies and modifications to their home themselves. Discussing the topic with the rest of the SRPFG revealed a range of costs people had incurred since having their stroke such as increased heating bills for those less mobile sitting at home for great lengths of the day, maintenance costs for mobility scooters, and higher premiums for holiday insurance. Although costs of stroke have been investigated at the national level in terms of cost of stroke to the NHS and the economy (National Audit Office 2005), at the time of initiating the research only one published study had looked at the personal costs, or ‘out of pocket’ costs, of stroke to individuals and their families (Dewey *et al.* 2004).

A pilot study investigating these questions was undertaken with SRPFG members and SRP researchers. The pilot involved developing a questionnaire with members of the SRPFG to be answered by 50 respondents on the Register. It is not the purpose of this chapter to detail the specifics of the pilot and a detailed report of the pilot methods and results are reported elsewhere (McKevitt *et al.* 2010a; see Appendix XIII

Publications arising from this thesis). Of greater interest for this chapter is the response of SRP researchers to a research question identified by stroke survivors.

Researchers' response to user identified research

I presented the results of the pilot to SRP researchers at one of the regular lunchtime meetings where researchers presented work in progress or the results of completed research. My intention for the session was to present the results from the pilot study and then direct the discussion towards developing the pilot study into a grant application for a properly funded research project. The Head of the SRP was the first to speak. He steered discussion away from developing the pilot into a fully funded research study to a discussion on writing up the pilot study as an experience of user involvement. He asked me if that was planned, or even possible, and more importantly would any high impact journals accept this type of publication. From his perspective, the value of enacting user involvement lay in the possibility of gaining a publication on our experience of involving service users in research. There was less interest in stroke survivors identifying research questions and these questions informing the research strategy of the SRP. Reinforcing this belief, the response of a number of health economists who the PI and I had approached for their input into the study[36], had been lukewarm.

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[36] The Head of the SRP indicated that a health economist needed to be a collaborator in such a study if it was to have any academic merit.

Derin, the health economist, argued that the question was of little interest to him as a researcher. In terms of health economics research, he continued, the question had little relevance as the out-of-pocket costs for individual stroke survivors were insignificant compared to the costs of stroke to the economy and to the NHS. The publication of similar out-of-pocket costs studies in a range of health fields (for example see Brooks *et al.* 2011;Essue *et al.* 2011; Wolfe & Michaud 2009) and media interest in the cost of ill health (Phillip 2006), suggests that the topic is of interest to researchers, patients and the general public if not to health economists working in the field of stroke. As I have already shown, this health economist thought that stroke survivors were unqualified to identify research questions as they were inherently non-objective owing to their status as patients or service users.

The results of the pilot study and the user involvement experience were published in an academic journal (McKevitt *et al.* 2010a). Publication in an academic journal took priority over publishing the results of the pilot in *Forward*, the SLSR newsletter (see Appendix XII). On the whole journals will only accept a paper for publication if it has not been previously published. The PI and I could not get clarification from the journal lawyers whether or not *Forward* constituted a publication. So to be sure of getting our paper published we waited before presenting results to stroke survivors via the newsletter – a clear example of where the interests of those who generated the research question and provided data for the research were the last to read of the results of the research.

Therefore, this research question on out-of-pocket costs, as identified by stroke survivors, was dismissed as irrelevant by a subset of researchers within the SRP who held the monopoly over what constitutes valuable economic research knowledge. The only value that this example of user identified research was seen to have was the potential to produce new health service research and sociological knowledge, published in academic journals, on the phenomenon that is user involvement in research.

Lukes' notion of inertia as a dimension of power (Lukes 2005;Lukes & Haglund 2005) can help us to understand the power relations at work in the example described above. Lukes and Haglund cite inertia on the part of the United States in climate change talks as an example of power. The USA exert their power by *not* participating in climate change talks and refusing to sign international agreements to reduce emissions. Similarly in the ethnographic episode described above, power was exerted by professionals through encouraging involvement in generating new research questions but not necessarily turning these questions into research studies. However, inertia does not fully explain the situation. Not only were researchers failing to act on ideas suggested by stroke survivors but as researchers we used the policy imperative to meet our own needs – namely increasing research output through publication.

Patient and professional understandings of research

For researchers the SLSR is an epidemiological tool mapping stroke incidence and outcomes at the population level. However, some Register participants (both those participating in the SRPFG and those who did not) conceived the purposes of the

Register and wider stroke research differently. This had implications for the activities undertaken within the user group and who ultimately controlled and made decisions about what user involvement in the SRP would entail.

Throughout my fieldwork stroke survivors discussed being on the Register in terms of the service they felt it provided with the yearly check-ups ‘to see how I’m doing’. SLSR participants saw the Register as an extension of the health service and care they had received in hospital at the time of their stroke. Register researchers and fieldworkers were thought to be health care professionals visiting to give an annual check-up. On one occasion I spoke to Mr Peters, a stroke survivor about his potential involvement in the Transforming Stroke Service Project (TSSP). Although Mr Peters was not interested in taking part in the TSSP, he wondered if I could help him to find out when his next appointment was. Mr Peters explained that when he was in hospital following his stroke he was signed up to something where someone would come and check up on him. However, he was starting to feel a bit concerned as nobody had been in touch for a long time. He asked me if I knew why this might be and if I could find out when they would get in touch. I said that it sounded like he was signed up to the South London Stroke Register. I explained that a researcher would come and visit him three months after the stroke, then six months and then yearly. So, if he had had his stroke a while ago then he would probably only be visited once a year now. Mr Peters said that would explain why no one had visited him in a while, but added that ‘they had better come and see me soon’ as he really thought ‘a visit was overdue’.

Similarly, researchers who were employed to collect data from Register participants felt that some participants were not fully aware that they were taking part in a research study as this extract from an interview with Sam and Isla, two Register researchers, illustrates:

> Sam: I think when I see [patients] at the initial stage, so much has happened to them with having a stroke that I don't actually think they're understanding what you're telling them. And although you do tell them precisely that it's not anything to do with their medical care, I think at that point they're in hospital, you've mentioned their consultant's name, that they just therefore think that it's something that's going to benefit them and so they say yes. So at that point I don't think they understand what they're committing themselves to.
>
> Isla: I agree with that, because I think that reflects when we go and see people at home and they, especially at the beginning, especially three or six months, all people we haven't seen yet, they definitely think you are part of, they'd call you stroke nurse or from the stroke unit or registrar, you know, so it is very common. I think very few people know that you are actually doing research, although we say that to them. We always kind of make sure they know that, but I think also, maybe given the kind of age of the people, because they are elderly, they just kind of see you as someone who comes. And some of the questions, because we look at the medications and take their blood pressure, so they kind of think we are somebody who looks after them. And even the nursing home [staff] kind of, once you've finished with a patient or looking through the notes, they kind of say, so will you be sending us a report?
>
> Interview with Sam and Isla, 12th December 2007

Being on the Register then, was seen to be part of the care one would hope to receive after being discharged from hospital. Given that one of the criticisms of stroke care both locally and nationally has been the lack of care and support patients receive once discharged from hospital it is not hard to see why Register participants attach such importance to the annual visits from fieldworkers.

At the introductory meeting prior to establishing the SRPFG, the PI and I had asked the stroke survivors attending what topics or questions relating to stroke they thought

ought to be researched through the Register. Most people talked about the possibility of the Register providing information to participants on how their health progresses from year to year. The PI explained to the group that the Register was not there to provide data to individuals, this really being the responsibility of General Practitioners (GPs). The PI continued with his explanation: whilst it seemed that many people were not getting the information about their stroke which they would like, the purpose of the register was not to provide individuals with personal information, but rather to conduct research to make policy makers and health care professionals aware of this unmet need.

On another occasion a researcher, Zoë, attended a SRPFG meeting to present the results of an interview study with stroke survivors for her doctoral research on secondary prevention of stroke. Zoë presented the results of her research and illustrated the points she was raising with extracts from the patient interviews. Zoë read out the interview extracts as they were displayed on the large screen we used in the meetings to project the PowerPoint presentations. One interview extract referred to ‘Kerry’, a woman in her 40s who had been suffering depression since having her stroke and as a result had started drinking alcohol excessively. Zoë read out aloud the words from Kerry’s interview: “Yes, I seem to have got worse over the years. Because there’s nothing for you to do, you get bored, and the only source of comfort is drinking booze and cigarettes, it’s a bad cycle”. On hearing and reading this extract the group members expressed concern for Kerry’s welfare and asked Zoë, ‘Well what did you do to help her?’ Zoë replied that she had not done anything but had told Kerry to speak to her GP about her depression. The group were horrified that Zoë had not sought help from a doctor on behalf of Kerry. Zoë tried to explain that as researchers our job is not to intervene but to observe what is happening or not and report these so that the relevant health care professionals or policy makers can make the necessary changes that are required. Conflict arose between stroke researchers and stroke survivors over what action should be taken if, in the course of data collection for the Register, a participant was found not to be receiving appropriate health services after their stroke. It was difficult for SRPFG members not to see researchers as connected to the health services they were researching, and consequently SRPFG members felt that researchers should intervene. Researchers however, felt that this was not their role as the Register was not intended as an intervention tool but as a means to observe and record what is happening, or not happening, at the population level.

This interpretation of research as a 'service' was further observed during discussions about content for the Register newsletter. The Register newsletter was an early outcome of the user group. In the first meeting the PI had said to the group that researchers had been particularly bad at feeding back the results of research to those who had taken part in the research. Group members thought the newsletter was a positive step, particularly given that they saw researchers as 'the experts' providing them with information on stroke. In the beginning SRPFG members took some control and ownership over the newsletter; coming up with the name for the newsletter, 'Forward'; expressing views about how it should look, 'something homemade, nothing corporate and expensive looking'; and suggesting content. However, whilst the PI and I saw the newsletter as a vehicle for disseminating results of Register research, group members had other ideas about the kinds of things they would like to see in the newsletter.

As previously discussed in this chapter, the topic of healthy eating frequently arose in meetings and in the context of the newsletter. In one meeting Pauline responded to the PI's request for article suggestions for the next issue of the newsletter. Pauline said that she would like to see some recipes. She said that a lot of older people live alone so they might like to see some recipes for cooking for one with a microwave. Pauline continued saying that she had found a 'nice recipe for a cake that only takes four minutes in the microwave, although actually it comes out more like a pudding so you have to eat it as a pudding with jam rather than as a cake.' As she was speaking Catharine was looking extremely worried at Pauline's suggestion. After Pauline had finished talking, Catharine asked if this cake was designed for people who had had a stroke. Pauline replied that 'it was from a packet'. 'There are lots of bad things in those cake mixes you know' Catharine said and went on to say how the *Co-Op* had just taken the decision to stop selling sweets and cakes specifically for people with diabetes because they were unhealthy. Whilst the stroke survivors attending that meeting dismissed Pauline's recipe as unsuitable for the newsletter due to its unhealthy nature, the PI dismissed the recipe column in its entirety as it appeared not to fit with the priority of disseminating research results.

However, on reflection, whilst the recipe column had little to do with research I was left questioning whether we as researchers should have taken a view of research as a ‘service’ or at the least a process which required reciprocating. The recipe column could have been a means to return the favour to stroke survivors for the time and commitment they give through participation on the Register.

To summarise, my observations have shown that stroke survivors involved in the SRP saw research as providing a ‘service’. Consequently the research user group, as a user involvement activity, did not always meet their needs for provision of individualised information or information about stroke which appeared to researchers to be unconnected to the work of the SRP. This had implications for researchers and the researched working as partners as they were coming to research from different starting points. The struggle to agree on ‘what research is’ was further compounded by stroke survivor and researcher understandings of the purposes of the user group and more widely user involvement, which I now turn to.

Patient and professional understandings of ‘involvement’

Through both interviews and observations it became clear that a primary motivation for stroke survivors to attend the SRPFG was because it provided a forum for meeting others in a similar situation, exchanging information about stroke and finding out about health and social care services they may be entitled to. For some stroke survivors, the group was a means of social participation – reducing isolation, and helping people to share and exchange stroke related information. It was common in the SRPFG meetings for members to use the meeting to make their own announcements. Robert was a former telephone engineer who had his stroke soon after he had retired. Robert would often bring along a newspaper cutting to share with the group about stroke – a critique of stroke services or a report on new developments in treatments for those who had had a stroke. He was particularly interested in articles relating to physiotherapy having felt, like most members of the group, that he had not received enough physiotherapy sessions since his stroke and this was the cause for his dependency on crutches to get about. Lily would bring in the latest Age Concern newsletter and information about local events or clubs that group members might be interested in. In this way the meeting was used by members to share information about stroke or other services which could be of interest or relevance to group members. These items were not connected to research but to the illness or condition and concern with the National Health Service that united the group. There was only one member who cited research as the primary motivation to attend the group: Anthony, who had just embarked on a PhD when he had a stroke. The SRPFG was a means to continue with his pre-stroke interests after the stroke left him aphasic and unable to carry on with his PhD research.

Stroke survivors' initial motivation for participating in the group was to receive support from other stroke survivors not available to them through other avenues. Although group members came to be interested in the results of stroke research, during a group discussion reflecting on the user group, only one stroke survivor cited research as the primary motivation for joining the user group. Researchers controlled the form of user involvement activities, for example by not allowing a recipe column to feature in a research newsletter, to ensure that their concept of research prevailed.

7.4. Conclusion

The requirement on researchers to involve stroke survivors in research was ultimately driven by DoH policy relating to research governance and research funding. Despite researchers enacting the policy and implementing activities to involve stroke survivors in research, researchers were openly critical of the policy. Furthermore, implementing user involvement in the SRP was as much about researching the phenomenon of user involvement as meeting research governance requirements.

As in the health service setting user involvement activities were driven by SRP researchers. A systematic approach was taken to recruit stroke survivors from a stroke register to avoid ‘proto-professionalism’ where certain types of patients, those deemed ‘appropriate’ for user involvement, are selected by professionals to be involved in research related activities. User involvement activities were conducted with stroke survivors forming a ‘user group’ and attending six-weekly meetings where stroke research was discussed. Stroke survivors attending the group were fairly representative of stroke survivors in the two boroughs in terms of age, gender, ethnicity, occupation prior to the stroke, and post stroke disability. Whilst there was variation within the group in terms of members’ ethnicity, social background and post stroke disability, what united the group was their prior status as active, responsible citizens concerned with civic engagement and the production and maintenance of their own health. With the exception of one or two members, most members had been active in the local community prior to becoming involved in the SRP. Similarly nearly all members were actively interested in managing their health whether this be through modifying their diet post stroke, adhering to medication regimens, following exercise programs, or keeping themselves informed of the latest developments in research and health through local and national newspapers. In this respect, the enactment of user involvement policy did little to create *new* subjects with a sense of civic responsibility and personal concern for health, as those participating in the group had already acquired this identity.

The implementation of user involvement in this setting served to maintain boundaries between researchers and the researched as the ‘user group’ was separated from the SRP and its researchers, physically and temporally. The user group met away from the main arena where researchers interacted with one another and made decisions about stroke research. Although user involvement may have rhetorical importance through policy requirements, in practice in this setting, as well as other settings reported in the wider literature on user involvement, there was a tendency for a certain category of researcher (e.g. social scientists, women) to take responsibility for enacting the policy of user involvement whilst the SRP as a whole benefited by being able to demonstrate that the policy was being adhered to. One of the policy aims of user involvement is to adjust the power between researchers and the researched. However, in this case, enactment of user involvement policy highlights power imbalances between different types of researchers. Through the enactment of user involvement policy in this way power was ‘insidiously’ exercised to maintain traditional hierarchies of the disciplines.

Finally, achieving the aims of user involvement policy aims were hard to achieve due to who has the right to determine the questions to create knowledge and differing concepts of ‘what research is’.

Chapter 8: Patient activism and user involvement

> I admire these young people for taking this job on because it's a thankless job, strokes. I mean it's not a glamorous thing, you know. It's not like looking into pregnancies where there's genes that are all wrong, and that sort of thing must be extremely, I would find more interesting than strokes. But for people like you to take it on, I think you've got, I admire you I really do, I think it's great, really I do. I'm not just saying that because you're here, you know I've said it before. I think it's wonderful that somebody's doing it and taking us seriously, you know.
>
> Interview with Irene, service user on TSSP, 10th March 2006

This extract from an interview with Irene, who cared for her husband after his stroke until his death, exemplifies the belief of many of the stroke survivors involved in the Transforming Stroke Services Project (TSSP) and the Stroke Research Programme (SRP) that 'strokes' were just not that interesting for those who had not had a stroke to be concerned with. Whilst many of the stroke survivors I met over the course of my research held a strong belief that their cause (improving the lives of those who had had a stroke) was important, they had little conviction that anyone not immediately affected by stroke would be interested in their cause or doing anything about it. In one of the SRP user group meetings William (who cared for his wife who had had a stroke and whom I first introduced in Chapter 6) summed up the inertia surrounding stroke by exclaiming that 'strokes just aren't sexy'. The other group members agreed and many suggested that stroke would only become a priority if ‘someone like Kylie were to have a stroke’[37].

In Chapters 6 and 7, I focussed on what occurred as the processes of user involvement policy implementation unfolded. Theoretical frameworks such as health social movement (HSM) theory (Brown & Zavestoski 2004) and biosociality (Rabinow 2008) suggest new social formations based around a shared biological identity. As professionals implementing user involvement we tried to capitalise on this, but what happened was something quite different from that envisaged theoretically. Therefore in this chapter I explore the relationship between these theoretical frameworks and what happened as we tried to involve stroke survivors in stroke research and service development. I apply Lukes’ three-dimensional view of power (2005) and HSM theory to explore the possible reasons why a stroke survivor activist movement has failed to develop in the way that survivor movements have arisen and grown in other health fields such as mental health, breast cancer and HIV/AIDS. Following Lukes, I will argue that as ‘power serves to create power’, stroke survivors’ sense of ‘powerlessness serves to reinforce powerlessness’ (Gaventa 1982: 256). By this I mean that patterns of acquiescence associated with stroke, such as the views described in the opening to this

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[37] In 2005, at the age of 37, Australian pop singer Kylie Minogue was diagnosed with breast cancer, raising the profile and public awareness of the disease through national and international media. The increase in breast cancer awareness, particularly among younger women, became known as the ‘Kylie Effect’. However, the ‘Kylie Effect’ has had negative consequences. The awareness that younger women can develop breast cancer has led some women to reach incorrect, age-related conclusions about breast cancer – that breast cancer risk is higher for women under the age of 50 when in fact the opposite is the case: breast cancer risk increases with age, and four out of five women diagnosed with breast cancer are over the age of 50. (Cancer Health 2012;Chapman *et al.* 2005).

chapter, may explain the apparent inertia surrounding stroke. Both Gaventa (1982) and Carney (2010), argue that a lack of political activism should not be attributed to the failure of people to mobilise, but rather we must apply critical concepts such as Lukes' three-dimensional view of power to understand how routines of non-conflict shape and maintain future actions, creating socio-economic dependency as well as political inactivity.

HSM theory may not immediately appear applicable to user involvement policy. Social movements have tended to form through the grass roots mobilisation of a group of people sharing a common identity seeking to challenge and transform dominant ideologies and practices. UK user involvement policy on the other hand, whilst employing the rhetoric of citizen-led transformation, has been driven by government agencies with the onus for policy implementation resting with health care professionals and researchers. However, both health social movements and the implementation of user involvement policy involve challenges to medical authority and the formation of new relationships between experts and patients and the public.

In this chapter, whilst I draw on Embodied Health Movement (EHM) theory as the traditional theoretical framework to explore patient activism I shall also allude to the concepts of biosociality and biological citizenship. Following Klawiter (2008), the broader meaning of the concepts – how the practices of medicine, health service delivery and public health research shape the formation of new subjects and citizen and patient groupings – is relevant to discussion on stroke survivor mobilisation and user involvement policy, particularly as Klawiter argues that the relationship between medicalization, biosociality and social movements has received little attention.

Social movements dealing with health can influence the health care system and are a major force for change in wider society. Certain health domains such as HIV/AIDS and breast cancer, however, have been more successfully incorporated into a movement compared to other health domains, such as stroke. Allsop *et al.* (2004) argue that those afflicted with a condition are drawn towards a social movement because they feel marginalised by dominant social practices. The sharing of a positive sense of identity attracts followers and the interaction helps individuals to find an explanation for a life event, forge a collective identity and a set of perceptions and ideas on how action should be mobilised (Allsop *et al.* 2004).

My interest, however, lies with investigating what happens when those afflicted by a condition are drawn together by professionals as the ethnographic findings from the two previous chapters suggests. In this chapter therefore, I investigate the theoretical fit between EHMs and movements which have been promoted, established and led by professionals rather than patients. This is coupled with a need to understand why stroke survivor mobilisation has not occurred despite there being plenty of reasons which could galvanise stroke survivors to protest.

I will use data from my observations and interviews conducted in the TSSP and SRP as well as the stroke literature to investigate whether the social groupings established through user involvement activities in the TSSP and SRP can in some way be described as an embodied health movement. First, I focus on EHMs and the theories put forward to explain the formation of these movements. Second, I discuss an apparent lack of protest observed in the two enterprises where I conducted the research despite stroke survivors on numerous occasions discussing the need for protest to engender the changes they wanted to see in stroke care. In the third section, I discuss the possible reasons which prevented stroke survivors mobilising into an embodied health movement, before concluding the chapter with discussion on the implications of an EHM analysis for user involvement policy.

8.1. Embodied health movements

In Chapter 1, I outlined a typology of HSMs, divided into three ideal, but overlapping, types of health social movement: embodied health movements, health access movements and constituency-based health movements (see Chapter 1, section 1.4 'Social movements in health'). This section focuses on EHMs as a particular form of HSM. I set out the theory of how embodied health movements have arisen in order that this theory maybe applied in subsequent sections to the case of stroke and to investigate the potential of user involvement as a patient movement. The section is in three parts and outlines the three defining characteristics of an EHM: first, the social construction of an illness identity; second, the challenge to medical knowledge; and third, collaboration with scientists and health care professionals.

The social construction of an illness identity

Like other health social movements, EHMs depend on the emergence of a collective identity as a mobilising force. Most participants in such movements have arrived at their activism through experiential knowledge - a direct, lived, felt experience of illness and their identities have often been shaped by this experience (Brown *et al.* 2004). Brown *et al.* argue that forming alliances with other illness sufferers through a collective illness identity may be sufficient to form a support group or a self-help group. However, in order that a '*politicised* collective illness identity' can emerge the collective illness identity must be linked to a broader social critique of the illness. (Brown *et al.* 2004: 60). In other words, patients must come to a shared understanding that structural inequalities and the uneven distribution of social power are responsible for the disease and the problems sufferers' experience. This effectively transforms 'a personal trouble into a social problem' (Brown *et al.* 2004: 61).

Brown *et al.* have coined a further concept, 'oppositional consciousness', linked to the notion of politicised collective illness identity (2004: 61). The authors propose that oppositional consciousness reflects a 'state of mind' that binds members of a group against dominant ways of thinking, for example, the dominant epidemiological paradigm, by attributing problems and grievances to structural factors' (Brown *et al.* 2004: 62). It is through the development of oppositional consciousness that those with grievances relating to their illness or condition politicise their collective illness identity.

To illustrate this point a number of authors have used the example of breast cancer activism in the United States of America (USA) (Anglin 1997;Brown *et al.* 2004;Klawiter

2004;Klawiter 2008;Kolker 2004). In the 1970s breast cancer was constructed as a problem affecting individual women who dealt with it privately. Klawiter (2008) conducted participant observation and interviews amongst breast cancer activists in the San Francisco Bay Area of the USA. She reported that in the 1980s there were few support groups for women diagnosed with breast cancer, apart from a peer support programme, ‘Reach to Recovery’, for women who had had a mastectomy. However, the goal of the ‘Reach to Recovery’ programme was to ‘normalise’ the disease, to help the post-surgery patient return to her former life and person prior to the cancer diagnosis and the mastectomy. The programme, however, was not concerned with challenging medical authority on breast cancer (Klawiter 2008: 118). The causes of breast cancer were laid at the door of the individual with the disease through their diet, lifestyle and reproductive choices (Anglin 1997). This changed, however, in the 1990s when scientific evidence reported that the incidence of breast cancer in the Bay Area was the highest in the world yet experts could not explain why this was the case. Driven by these scientific findings a movement of women with breast cancer was formed. Breast cancer activists focused on the environmental causes of the disease (activists reported that breast cancer victims contracted the disease from toxic material which littered the Bay Area) and the failure of the government to prioritise the disease which disproportionately affected women rather than men (Brown *et al.* 2004;Klawiter 2004;Kolker 2004). Thus, Klawiter (2004;2008) argues that breast cancer was redefined as a public health priority; a social problem that individuals should not have to quietly deal with alone.

Kuhlmann *et al.* (2009: 519) note that the success of health social movements is not just about protest actions (marching, testifying, lobbying), but concerns how the condition is defined and understood publicly. Kolker (2004: 836) argues that an important component in the breast cancer movement's efforts to increase research funding in the 1990s was the use of 'culturally resonant' frames to 'connect with and persuade public audiences'. The breast cancer movement used a number of frames (gender equity, the environment, the erosion of the family), to reconstruct breast cancer from a private individual problem to one of public health significance in need of government intervention. Activists constructed breast cancer as a female disease, despite the fact that men can get breast cancer. The use of a gender equity frame allowed activists to position breast cancer as a threat to their gender as well as to criticise the government for neglecting a disease which disproportionately affected women rather than men. The gender equity frame was easily mobilised by activists and understood by the public as it had been used previously in feminist movements and women's health movements in the USA. Activists created a deeper sense of public concern about breast cancer by framing the disease as a 'serious threat to American families' by characterising the women who would die from breast cancer as family members (grandmothers, mothers, wives, sisters, daughters) whose death would damage the stability of the family. This further legitimised their demands on increasing government funding on the prevention and treatment of breast cancer as this would contribute to the stability of the family (Kolker 2004: 831). The ability of other illnesses and conditions, such as stroke, to attain public resources depends on how effectively they can appropriate the resonant frames of other successful health social movements. Kolker's study therefore, raises questions about how other social movements linked to health might utilise cultural resources to further their cause.

Challenge to medical knowledge and practice

The second defining characteristic of EHMs is that they challenge existing scientific and medical knowledge and practice. This challenge, which sets EHM apart from other social movements, is based on 'intimate knowledge and first-hand experience of the body and the illness' (Brown, *et al.* 2004: 64). In the case of HIV/AIDS in the early 1980s, scientific knowledge about HIV/AIDS was limited. According to Epstein (1996) that knowledge which had been acquired was of little interest to the prestigious medical journals. HIV/AIDS activists had to challenge the political, scientific and medical élites to ensure that clinical research led to the development of effective treatments that were warranted of such a deadly illness (Epstein 1996). Epstein opens his book charting the rise of HIV/AIDS activism with a description of HIV/AIDS activists from the Boston chapter of ACTUP[38] protesting at the start of a new academic year at Harvard Medical School. The protestors handed out a mock course outline for an 'AIDS 101' class with discussion topics such as:

> PWA [People with AIDS] – Human beings or laboratory rats? AZT – why does it consume 90 per cent of all research when it is highly toxic and not a cure? Harvard run clinical trials – Are subjects genuine volunteers, or are they coerced? Medical elitism – Is the pursuit of elegant science leading to the destruction of our community? (Epstein 1996: 1).

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[38] ACTUP (The AIDS Coalition To Unleash Power) is a voluntary organisation which utilises direct-action and protest to challenge legislation, medical research, treatment and policies in order to end the AIDS crisis (ACTUP/NY 2012).

As the above quote illustrates, the protestors were not rejecting medical science. On the contrary, they were denouncing the practice of a form of science, ‘elegant’ or ‘good’ science, which the activists believed was not conducive to medical progress and the health and welfare of their community.

Collaboration with scientists and health care professionals

With dependence on science at the heart of EHMs, the third defining characteristic of EHMs I will outline is the collaboration of activists with scientists and health care professionals in pursuing treatment, prevention, research and increased funding (Brown *et al.* 2004). Lay activists within EHM strive to collaborate with scientists so that their illness experience can help to shape research design.

According to Hess (2004) modern scientific medicine is undergoing increasing challenges to its epistemic authority, in part due to the rise in EHMs and other health movements falling under the umbrella of HSMs. Hess argues that whilst patients have long experienced scepticism towards their doctors, the dominance of medical expertise has endured and been tolerated due to the dependence of the patient on the doctor. However, since the 1960s and 70s, the growing acceptability of lay challenges to scientific and expert authority, increased scepticism and civil society mobilisation in light of a number of research misconduct scandals (see Chapter 1 for a fuller discussion of these points) together with the rise of disease-specific EHMs has challenged the authority of the medical profession and health research community. Compared to other health movements, based for example on access to health care, scientific knowledge plays a greater role in EHMs (Brown *et al.* 2002*)* as patients experience a disparity between their ‘illness’ and the official systems of diagnosis and treatment of the ‘disease’ (Hess 2004: 697). Therefore, the emergence of HSMs and in particular disease-based, EHMs, has altered the relationship between the medical research community and the public from a relationship of dependence to one of collaboration (Hess 2004). Having outlined the defining elements of EHMs, and illustrated EHM theory with examples of successful EHMs such as breast cancer and HIV/AIDS, in the next section, I focus on the case of stroke and the absence of an EHM.

8.2. The absence of a stroke embodied health movement

Previously in this chapter I have referred to successful EHMs in the fields of HIV/AIDS and breast cancer. In this section, I discuss the absence of a stroke EHM. In the case of stroke, this condition is not discussed in the HSM and EHM literature. Allsop *et al.* (2004) conducted research to map the activities and characteristics of health consumer groups across the UK. The research identified few consumer groups formed by patients and carers in the field of heart and circulatory disease. Additionally, as I reported in Chapter 1, to date, stroke is less well developed in professionally-led forms of patient mobilisation, such as user involvement activities, compared to other health conditions (see Chapter 1, section 1.5 ‘The case of stroke’). This is despite there being a number of reasons (a history of poor quality stroke services and low levels of research funding) which could galvanise stroke survivors to mobilise and protest. After discussing the absence of a stroke EHM, I investigate whether implementation user involvement activities in the two enterprises where I conducted my research facilitated the development of an EHM of stroke survivors. I will argue that whilst user involvement activities helped to engender a collective illness identity (in other words, the first characteristic of Brown's classification of EHMs), a politicised collective illness identity and challenge to medical knowledge and practice was harder to achieve.

Anglin (1997) has argued that a similarity between HIV/AIDS and breast cancer is that they were both 'incurable' diseases which led to a movement of those with the condition to fight for treatment development. Stroke can be seen in a similar frame. As I have alluded to earlier in the thesis, stroke may have a considerable impact on the individual who has the stroke and their family, and has implications for wider society, yet historically stroke has received considerably less political, financial, medical and scientific attention in comparison to other health fields such as heart disease and cancer (Rudd *et al.* 2005), and in the UK, stroke care has been characterised as a neglected clinical speciality (Wolfe *et al.* 2001).

The funding of stroke research has been characterised as inadequate. Worldwide stroke research has consistently been underfunded compared to coronary heart disease (CHD) and cancer (Pendlebury *et al.* 2004;Pendlebury 2007). In a study of research funding across nine European countries, Pendlebury *et al.* (2004) found that stroke research received less funding than that received by cancer, usually by a factor of 2:10. In every country except Turkey, funding for stroke research was less than that for CHD. In a later publication, Pendlebury (2007) argued that without better funding for stroke research it is unlikely that progress and treatment will offset the projected increases in the burden of stroke.

Stroke is largely a preventable and treatable disease (Addo & Wolfe 2011), yet much of the technological and medical advances have focused on dealing with the effects of stroke once it has occurred, rather than preventing it in the first place. Much hope has been placed on one technological development – thrombolysis. Thrombolysis is a clot busting drug, suitable for those who have had an ischaemic stroke, where the supply of blood to the brain has been prevented by a clot. However, thrombolysis is not suitable for all patients with ischaemic stroke. For example, the drug must be given within four and a half hours of the onset of stroke symptoms which requires the patient to know when their symptoms started and to get to hospital within the treatment 'time window', and patients who are at risk of bleeding cannot be given the treatment (Cluckie *et al.* 2012; Rudd *et al.* 2005). Thrombolysis has been licensed for use in the UK since 2003, but uptake of the treatment has been slow. At the time of fieldwork only 3.8% of stroke patients were being thrombolised (Royal College of Physicians 2010). Since the publication of the Department of Health's Stroke Strategy, a strong emphasis has been placed on treatment in the initial stages of stroke in hyper-acute stroke units and on greatly increasing the proportion of patients being given thrombolysis. Concerns have been raised that many other effective components of a comprehensive stroke service might not receive as much attention as a result (Sudlow & Warlow 2009).

Aside from the concerns raised by clinical researchers (Sudlow & Warlow 2009), there has been little pressure from stroke patients for researchers to pursue and research other forms of stroke treatment. This is in contrast to HIV/AIDS activists in the USA who actively pursued researchers to develop new drug treatment regimens and press politicians for easier access to experimental drugs available in other countries (Epstein 1996). I now turn to focus on whether the implementation of user involvement activities led to the development of a stroke survivor activist movement.

The collective illness identity of stroke

Members of the various ‘user groups’ established across both enterprises where I conducted the research were focussed on the illness, the stroke, which had brought them together. Whether they were the informal carers of a stroke survivor or had had a stroke themselves, those participating in the TSSP and SRP had a constant need to tell and retell their stroke story. These stories were repeated, word for word, numerous times over the course of my observations. Often, the story teller would precede their account with an apology for repeating him or herself. Yet, he or she would still go ahead as if the urge to narrate and convey the story was beyond their control. Irene, who is quoted at the beginning of the chapter, was a case in point.

Irene was in her 80s and had lived in Southwark all her life. She cared for her husband, David, who had had a stroke which had left him needing a lot of looking after, attention and support. In her spare time, Irene ran a pensioners’ group and in her ‘pre-retirement’ days had volunteered at the local hospital working on the refreshments trolley, selling sweets, newspapers and magazines to patients. During user group meetings, and during an interview with me, she frequently retold the story of the moment when she finally had an understanding of what the stroke had done to her husband's brain. 'I know I keep going on about this', she would say during a meeting, 'but it is important that people know: the best way to explain the stroke was like a computer having it's plug pulled out' and losing all its information and 'over time you've gradually got to teach it how to do things again'. Irene would continue, reeling off tips she had picked up through caring for her husband. For example, she found that her husband would only eat food from the left hand side of the plate. The spatial neglect[39] that David suffered as a result of the stroke meant that he was unable to pay attention to the food on the left-hand side of the plate. Irene discovered that if she simply turned the plate around as they were talking over the meal he would then eat up all the food on his plate, ensuring he ate well.

Jim, who I introduced in Chapter 7, was another frequent raconteur of his stroke story. Jim's story related to his experience with a physiotherapist and the story would be told whenever the topic of physiotherapy arose in one of the user group meetings (Jim was a member of a number of user groups in both the TSSP and SRP). Jim would say:

> Well I keep plugging it, but I think my, the importance to me is the physio. I was stuck in a wheelchair when I was in Dulwich hospital and my sister came up to visit and she said to the nurse, "Why isn't Jim having physio?" And she was told I'd never walk again. But when I left the hospital I went into a nursing home because I wasn't in a

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[39] Spatial neglect or inattention, is a problem with paying attention to or responding to objects, people, or one's own body on the side opposite to where the stroke or brain injury occurred. Neglect can involve all the senses, such as vision, touch, or hearing, but it is not due to the loss of these senses but rather a deficit in attention to and awareness of one side of the body.

> state to go home. So I was just stuck in a wheelchair and the only way of getting in and out of the wheelchair was in a hoist. And then I was referred to St Thomas' Hospital where I met up with a physiotherapist, Ken. Saint Ken I call him. Three times a week he would put me on a tilt board, strap my legs down, as my ham strings had shortened. It was very, very painful but I used to look forward to it because he was convinced he could get me walking, and he did.

Both Jim and Irene remarked that their motivation for joining the user groups was to meet others in a similar situation, to impart their knowledge, thereby helping others. Belonging to a user group within the TSSP provided Irene with the outlet she needed to pass on the knowledge she had acquired over the years of caring for her husband after his stroke, as the following extract from her interview illustrates:

> I [felt] so inadequate once David had died, because obviously my whole 14 years was spent, I mean I knew every hair on his head, you know, how he was and everything and of course I was left with nothing. And I did feel that I'd got all this, I mean I'm not bragging about this, it just so happened that through the years you get all this information, though you don't realise it at the time, and then, you know, your knowledge is nothing, All you know, you know, is there [Irene gestures to her head] and unless you spit it out, as it were, being rather vulgar, but you know what I mean, unless you open it up nobody's going to benefit, because you know you haven't said. So when this project [the TSSP] came along I thought well that's absolutely ideal because if I could empty my head of all this so-called knowledge, tips, whatever you like to call it, I would really feel that I'd helped somebody, even if it was only one person. And so it was an outlet for me. … And it has been extremely helpful as far as I'm concerned, because as I say, not only I've given, but for the people that have come up to me and said, "Well I've identified with what you've said" … and I've come home feeling great.
>
> Interview with Irene, stroke survivor on TSSP, 10th March 2006

Irene commented during the interview that, aside from the TSSP, there was 'no other outlet' available to discuss stroke with others in a similar position. This was a view shared by the majority of stroke survivors participating in the various user involvement activities across the TSSP and SRP. Therefore through the shared identity of the stroke, the ‘user groups’ performed a role as a support group for stroke survivors. The only place where stroke survivors refrained from telling their stroke story was in the TSSP Management Group meetings. This was possibly because those stroke survivors participating in the group were in a minority compared to the number of health care professionals and NHS managers present in the meetings, and they did not see this user involvement activity as having a ‘support group’ function. Furthermore, the formal business nature of the meetings prevented stories of a confessional and experiential nature from being told. Therefore it was only certain practices of user involvement that engendered a collective illness identity.

Whilst the majority of stroke survivors participating in the TSSP and SRP identified with their stroke and were keen to recount their stroke story and listen to the stroke stories of other survivors, there was another group of stroke survivors who were less keen to share this identity. These were stroke survivors I spoke to on the telephone during the process of inviting and recruiting stroke survivors to participate in either the TSSP or SRP. These people declined to participate in the stroke user groups as they told me they did not want to focus on the stroke, preferring to focus on getting on with their lives, or that the stroke had had minimal impact on their lives and was therefore not a significant factor in their lives.

So, whilst engagement of stroke survivors through user involvement activities helped to foster a collective illness identity, not all stroke survivors I had contact with through the course of the research shared this identity. Furthermore, stroke survivors in the two enterprises where I conducted participant observation did not develop ‘oppositional consciousness’. Thus a politicised collective illness identity, a key component of an EHM, was hard to achieve. In their deference to researchers and health care professionals as ‘the experts’ stroke survivors focused on the individual causes of their stroke such as lifestyle choices, hence the emphasis some members put on the type of food that was provided at user group meetings (see Chapter 7). Although some stroke survivors attempted to link high blood pressure to stress caused by inappropriate housing situations and negotiating and navigating complex health and social care systems (see chapter 6 for a fuller discussion on this point) there were fewer grievances directed at the government, the health service or society for the structural inequalities which exist within stroke medicine and research, which I discuss below.

The lack of protest

Drawing on Della Porta and Diani’s (2006) definition of social movements as ‘informal networks based on shared beliefs and solidarity which mobilise around conflictual issues and deploy frequent and varying forms of protest’, Brown *et al.* define health social movements as ‘collective challenges to medical policy and politics, belief systems, research and practice that include an array of formal and informal organisations, supporters, networks of cooperation, and media (Brown *et al.* 2004: 52). One aspect from the definition of social movements that seemed to be missing from the ‘user groups’ I observed is that of ‘protest’. Della Porta and Diani define and characterise protest as ‘nonroutinised ways of affecting political, social and cultural processes’ with the ‘capacity to mobilise public opinion through unorthodox forms of action', putting pressure on decision makers (Della Porta & Diani 2006: 165). As I argued in Chapters 6 and 7, the form and activities of the various stroke user involvement initiatives were largely determined by professionals. Stroke survivors were invited to participate in stroke service development or stroke research by professionals, in a professional space. Whilst user involvement policy aims to achieve a transformation of professionals and patient roles, I observed little evidence of this and stroke survivors did not necessarily see it as their role to challenge professionals.

EHMs require a challenge to expertise and therefore blur the boundaries between experts and lay people. Boundary movements gain power by 'obscuring the boundary between the expert and the lay person' (Hess 2004). However, in the enactment of user involvement I observed, this blurring of boundaries did not occur.

User involvement proposes that experiential knowledge of an illness is a form of knowledge that will improve health service development and research. Whilst experiential knowledge was, within certain limits, taken for granted in the two enterprises where I observed the implementation of user involvement activities, stroke survivors tended to defer to NHS managers and clinicians, and university researchers as 'the experts'. In the TSSP, whilst stroke survivors were encouraged to see themselves as experts in stroke, this knowledge was limited to the direct lived experience of stroke and providing information on how to live with stroke. Stroke survivors were less involved in the more medical and technical aspects of their stroke such as the provision of services in hospital or in the community once discharged from hospital. The lack of transformation of the 'lay' and 'expert' roles is reflected in a comment Kartik made to me about his experience of being on the TSSP Management Group. A number of senior clinicians who worked on the stroke units at King's College and St Thomas' Hospitals were members of the TSSP Management Group as part of their secondment to the TSSP. Most of those senior clinicians were working on the stroke unit which Kartik was admitted to when he had his stroke. Kartik told me that he found it 'weird to be on the same level as the people who treated me in hospital'.

In the SRPFG stroke survivors frequently deferred to researchers as the experts on stroke. Stroke survivors responded positively to presentations about the Register as recipients of knowledge generated by researchers. 'Thank you for enlightening me', Archie said, at the end of one meeting referring to the presentation the Principal Investigator (PI) had given about stroke research. 'Now I understand the Register and why I am on it', echoed Joan. SRPFG members who had had a stroke frequently apologised for their lack of mental capacity and disability following stroke which they said limited their capacity to take a more active role in the group. SRPFG members enjoyed coming to meetings, meeting others and listening about the results of stroke research. However, contrary to user involvement policy where 'user-led research' is promoted as a valid form of user involvement, SRPFG members did not necessarily want to take on an active role as a 'researcher'.

However, despite the apparent lack of protest or challenge to experts I observed, throughout my fieldwork stroke survivors talked of 'protest'. During an interview with Anita about her involvement in the TSSP I asked her what she thought about the government's attempts to encourage ordinary people to get involved in making decisions about health services and what happens in hospitals. Anita responded immediately, clearly demonstrating her knowledge of protest as the only means to achieve your aims:

> It's nothing new – this has been going on for centuries so why would we think it is something new? Women had to fight for their rights, tie themselves to railings things like that to [get the] vote, so why would we think it is something new? You have to campaign for anything you want – it's never given to you.
>
> Interview with Anita, 19th January 2006

Early on in the set-up of the stroke research user group, members talked about becoming a 'campaigning group'. Improving stroke services was coupled with a larger desire to fight for the NHS, which Catharine described as 'the only decent thing we have left'. Timothy, a stroke survivor and former naval officer, talked of the SRPFG becoming a 'ginger group'. A ginger group is a formal or informal group within a larger organisation or movement seeking more radical change to the policies and practices of the organisation or movement, while still supporting the general goals of the organisation or movement.

Pauline (who I first introduced in Chapter 7) was involved in the TSSP and the SRP. She and was seen as disruptive by the other participants (stroke survivors and professionals). This was because she consistently interrupting others who were talking in order to recount her stroke story and other life stories which were not particularly relevant to the items under discussion at the various user groups she attended). However, she was one of the few stroke survivors participating who regularly called for the 'big people' (meaning the people who have influence and control over the systems and processes under change) to be present in the various user involvement activities. Pauline challenged the Professor in charge of the SRP for leaving the introductory meeting to involve stroke survivors in research early. During interviews and telephone conversations I had with her she asked me why he did not attend the regular SRPFG meetings. She frequently voiced the need for stroke survivors to see the 'big people' at the user group meetings. However, these requests were not met in the SRP and were met on one occasion in the TSSP. Pauline withdrew her involvement in the SRP after about six months and was active in the TSSP for the first two years of the three year project.

In this section I have set out the absence of a stroke EHM. Whilst user involvement activities implemented in the TSSP and SRP helped to create a collective illness identity for stroke survivors, an EHM was not created because of the absence of a politicised collective illness identity and protest. In the following section, I discuss the possible reasons to explain these absences

8.3. Factors impeding the development of a stroke EHM

In this section I apply EHM theory to the phenomenon of user involvement to help explain why mobilisation of stroke survivors has failed to develop in the way other movements based around an illness identity have mobilised. I argue that the social construction of stroke has disempowered stroke survivors so that they acquiesce, become accepting of their situation and as a consequence protest is curtailed. The way the illness manifests itself and characteristics of the illness, such as tending to affect older people, prevents stroke survivors from acting collectively and mobilising.

I discuss four factors which have impeded the development of a stroke EHM: social construction of stroke; the association of stroke with old age; the manifestation and management of stroke as a condition; and the lack of ‘frames’ for stroke which limited the production of meaning in the process of action.

The social construction of stroke

Stroke has long been viewed amongst the medical profession as an illness which had little clinical interest or challenge and whose ‘victims’ were uninteresting and unwanted. In her study of stroke care and management in a Canadian general hospital in the 1970s, Hoffman (1974) categorised professionals’ view of stroke as ‘nothing can be done’ which fuelled professionals’ resentment towards caring for stroke patients. Hoffman found that professionals’ belief that ‘nothing can be done’ for stroke patients did not stem from the physical condition of stroke patients. Rather, it stemmed from the attitudes of health care professionals treating them which had been shaped by the hospital’s remit for rapid treatment and a continuous turnover of patients. The nature of stroke, a chronic illness with no ‘cure’, did not fit the goals of the hospital which was to treat acute episodes of illness, discharge patients, making bed space available for the next patient with an acute illness. Thus stroke patients, once they had been managed in the critical period immediately after their stroke, were then neglected as their needs seemed less urgent than those of other patients.

Similarly, in their study on delivery of stroke rehabilitation services in the USA in the 1980s, Kaufman and Becker (1986) reported that rehabilitation after stroke was devalued by health care professionals and considered to be on the periphery of health care on three accounts: the devaluing of rehabilitation within the health care system; a belief that stroke rehabilitation care is ideologically different from acute care medicine; and an association of stroke with old age. Rehabilitation professionals interviewed by Kaufman and Becker reported not having enough time to spend with stroke patients and that they were still too ill to respond to, or participate fully in, rehabilitation therapies. The priority of discharging patients quickly from hospital meant that patients started therapy still in shock from the stroke, exhausted, and unable to cope with the physical demands of rehabilitation. Medical insurance gave most patients only a limited time of six weeks to receive rehabilitation therapies when most rehabilitation professionals believed six to eight months was an optimal time period. Rehabilitation professionals reported that their approach to care differed considerably from acute care professionals. For example, they considered the goals of rehabilitation to focus on the areas of the brain which had not been affected by the stroke and finding ways to adapt to, and cope with, the changes brought on by the stroke. Much of the rehabilitation work required the patient and their relatives to do as much as possible for themselves, finding their own ways of coping and adapting. This contrasted with the acute medical view of treatment, which is performed *on* a patient *by* a professional, leading to a misunderstanding by the relatives of stroke patients that rehabilitation professionals do not 'do anything for them' (Kaufman & Becker 1986: 986).

Kaufmann and Becker found that an association of stroke with old age marginalised the status of stroke rehabilitation. The negative cultural values associated with old age as a time of sickness and death meant that rehabilitation professionals believed that declining functional ability with advanced age was normal and irreversible. This, coupled with a belief that older stroke patients have less motivation to recover owing to their acceptance of impending death, informed decisions made by professionals about the kinds of treatments offered to older stroke patients. As a result older stroke patients were less likely to receive intensive rehabilitation therapies.

I argue that the perception of stroke created through health services creates a sense of worthlessness leading to acquiescence on the part of stroke survivors. Following Lukes three-dimensional view of power (2005), the way stroke is perceived shapes stroke survivors' own perceptions, cognitions and preferences in such a way that they accept their position in the existing order of things, either because they can see no alternative to it, or because they see it as natural and unchangeable. I now turn to the second factor – the association of stroke with old age – which further impedes the development of an EHM through routines of acquiescence.

The association of stroke with old age

Although anyone can have a stroke at any age, the risk of stroke is greater the older a person is (Wolfe 2000). Previously, I discussed the link researchers have made between the perception of stroke as a normal part of the aging process and culturally negative associations of old age with the provision of poor quality stroke care (Hoffman 1974; Kaufman & Becker 1986). The negative association of stroke with old age was highlighted during a particularly awkward moment in one meeting of the SRPFG. The SRPFG had been regularly meeting for two years when two new recruits to the Register expressed an interest in attending the user group meetings. Markus and Barry, accompanied by their wives, attended their first SRPFG meeting about three months after being diagnosed with stroke. By coincidence they lived relatively near one another, were both in their early 50s and had been in adjacent beds on the stroke unit.

I had arranged for taxis to bring them to the meeting and so as it was their first meeting I waited outside the University Theatre where meetings were held for their taxis to arrive so that I could show them to the meeting room. Barry and his wife Katrina arrived first and my immediate reaction was that Katrina looked so young and glamorous that I wondered if she would identify with the other people in the group, some who would have been 30-40 years older than her. I had a feeling that their participation in the group would be limited to just that one meeting. This was confirmed towards the end of the meeting during a discussion about a research project on depression after stroke. Markus had had a particularly difficult time adjusting to the stroke and was suffering from depression, for which he had received little medical support. He remarked bitterly about the stroke that he had 'gone upstairs a young man and came down an old, disabled man'. Markus thus associated the effects of the stroke with becoming an old man. Other studies investigating stroke survivors' experiences of stroke have found participants making reference to old age in relation to stroke. Participants in Kouwenhoven *et al.*'s (2011) study referred to their lack of energy following their stroke as making them feel old. In another study exploring the meaning and experience of being a stroke survivor (Murray & Harrison 2004), participants regarded their appearance after stroke as being that of an older person.

A number of reports have been published detailing the neglect of older people receiving health and social care services and have argued that ageism is contributing to this poor care and neglect of older people (Parliamentary and Health Service Ombudsman 2011; Quality Care Commission 2011). Allsop *et al.* (2004) conducted research to map the activities and characteristics of health consumer groups across the UK. The research identified few consumer groups formed by patients and carers in the field of heart and circulatory disease, the exception being Different Strokes, a health consumer group established by, and for, *younger* stroke survivors. Allsop *et al.* report that research conducted in the USA found similar results, leading the authors to conclude that heart and circulatory disease does not appear to arouse feelings of anger and resentment, or pose a threat to identity (Allsop *et al*. 2004: 744). Similarly old age does not engender a public response. This, combined with a tendency for older people to be less likely to engage with and challenge professionals (Bentley 2003;Carney 2010) limits the potential for the development of a stroke social movement. However, a number of authors have argued that the relationship between citizenship and ageing will become increasingly important as populations age (Brown *et al.* 2004;Carney 2010).

The manifestation and management of stroke

Stroke manifests itself as an illness with a sudden onset. For most patients who have a stroke there will have been little warning of the impending stroke. As the name suggests, a stroke happens in an instant. A stroke therefore, differs in its manifestation from other diseases such as cancer or HIV where a diagnosis may be made long before presentation of the serious symptoms of the disease. As I discussed in Chapter 6, the management of stroke patients is different from patients with other long term conditions such as diabetes or kidney disease. Once stroke survivors are discharged from hospital, rehabilitation therapies are carried out in the community, often in the home, for a limited period of time. Stroke patients do not receive follow up care via an outpatient's clinic and in the area where I carried out fieldwork there were few stroke specific clubs or support groups. Thus the management trajectory of a stroke patient isolates stroke survivors from one another and limits the space and opportunities for a collective illness identity to emerge which could then develop into a politicised collective illness identity.

Producing meaning in the process of action

Previously, I discussed the concept of culturally resonant 'frames' to create meaning and garner public support for a disease. These frames can be particularly effective if they have 'spilt-over' from other social movements. Given that stroke is the leading cause of adult disability in the UK (Wolfe 2000) and the success of disability rights movements, an obvious frame to adopt would be that of 'disability'. However, stroke has tended not to feature within disability-related organisations. In Chapter 5, I referred to comments made by the chief executive of a local disability charity that stroke survivors had been ‘non-existent’ in the organisation, and research by Moss *et al.* (2004) which found that disability-related organisations excluded those with aphasia as aphasia was not considered to be a disability.

Brown *et al.* (2004) and Kolker (2004) argue that conceptual frameworks for the study of EHMs suggest that illnesses with no link to previous social movements will have more difficulty mobilising than those with clear links. For example, Brown *et al.* cite Alzheimer’s disease as having no clear link to a previous social movement. Consequently, those with Alzheimer’s disease and their carers emphasise awareness campaigns and resource advocacy within the mainstream medical system, rather than challenging dominant perspectives or seeking democratic participation in the research enterprise. Here, however, Brown *et al.* are referring to the situation in the USA and their example may not fit so well with the situation in the UK where service users within the Alzheimer’s Society have sought active participation in the research enterprise, including setting research priorities, prioritising and commenting on grant applications, sitting on grant selection panels, and monitoring on-going projects funded by the Alzheimer's Society (Alzheimer's Society 2011). Kolker argues that social movements may be limited by the social value of the group of ‘victims’ it portrays, having a negative impact on their ability to convince audiences that their disease is a serious public problem. The association of stroke with old age and the generally negative cultural associations surrounding ageing may limit the value of adopting ‘old age’ as a culturally resonant frame.

8.4. The implications of EHM theory for user involvement policy

In this chapter I have applied two theories to understand why a stroke survivor movement has not developed in the way that movements have manifested in other health conditions. I used Lukes' radical view of power as a rationale to investigate the notion of why things do not occur and how patterns of acquiescence might explain this absence or non-occurrence. In the case of stroke, I was interested in understanding whether patterns of acquiescence associated with stroke (the historically poor quality of stroke care, the lack of funding for stroke research, the association of stroke with old age) may explain why a stroke survivor movement has not occurred.

I applied EHM theory to examine whether the social groupings established through user involvement activities in the TSSP and SRP could in some way be described as an embodied health movement. The user involvement activities implemented in the two enterprises brought stroke survivors together, often the first time this opportunity had been available to stroke survivors. Through the narration of their stroke stories, stroke survivors were able to create a collective illness identity, the first of three defining elements of an EHM.

However, a *politicised* collective illness identity, a crucial element to turn a 'personal trouble into a social problem' (Brown *et al.* 2004: 61), did not develop meaning that the second and third elements of an EHM – challenge to medical knowledge and collaboration with professionals – were not met. I argue that the oppositional consciousness required to form a politicised collective illness identity did not occur on a number of accounts.

Until recently stroke had been viewed amongst the medical profession as an illness with little clinical interest or challenge and whose ‘victims’ were uninteresting and unwanted. This coupled with stroke being associated with old age leads to routines of acquiescence, whereby stroke survivors accept their position in the existing order of things, either because they can see no alternative to it, or because they see it as natural and unchangeable The current cohort of stroke survivors are of a generation new to the idea of patients challenging ‘experts’. Stroke survivors may therefore be reluctant to challenge researchers and health care professionals whom they see as ‘the experts’. However, this factor may change as a generation of stroke survivors used to challenging experts emerges. The manifestation of stroke and the way the disease is managed, physically isolated stroke survivors from one another making it harder for stroke survivors to meet collectively to form a patient movement. Finally the lack of culturally resonant ‘frames’ stroke could latch onto to create meaning and garner public support for the disease meant that a stroke EHM could not develop.

User involvement is positioned as a mechanism to create change in arenas of health policy, services and research. Social movements too have focused on success in terms of change in legislative and policy making arenas. However, Klawiter (2004: 866) argues that the most important measure of success in the impact of social movements is on the lived experience of ‘so called “free riders” and non-participants’. In other words, the success of a movement should be measured by how the lives of those with the illness who have not directly participated in the social movement have been changed for the better.

Proponents of user involvement have argued that user involvement will lead to the development of services which are more likely to meet the needs of the local community and in the case of research, more appropriate research questions, the research results of which are more likely to be put into practice. However, there is little evidence that these outcomes are being achieved through the implementation of user involvement activities. Furthermore, numerous studies reporting the benefits of user involvement refer to the impact of participation in user involvement activities on the individuals who have directly participated, such as an increase in confidence and knowledge, and gaining skills in new areas. For example, Horrocks *et al.*'s (2010) study of the involvement of mental health service users and carers in the planning, design and commissioning of mental health services in Lancashire indicated that whilst service user and carer involvement was considered a high priority, the Lancashire Partnership spent most of its time discussing processes and actions. Horrocks *et al*. report that where service user involvement resulted in better outcomes, these improved outcomes were limited to the individual service users involved, rather than better outcomes for all service users in terms of the service improvements made as a result of user involvement. As I argued in Chapters 6 and 7, the majority of stroke survivors who participated in user involvement activities in the TSSP or SRP tended to be those who were already engaged in active citizenship. At the level of implementation then, user involvement would appear to be less concerned with creating a movement of patients prepared to challenge professionals in order to change policies to help all patients but is a more limited process to open up the space for citizen engagement within certain parameters. This adds further evidence to that which I have already set out, that the practices of user involvement are not associated with health social movements.

Earlier in the thesis (see chapter 3) I introduced the concept of biosociality and biological citizenship. Biosociality conceptualises the link between the emergence of new groups and identities and new practices of science and medicine. Whilst biosociality was initially applied to genomics research and its clinical consequences, the concept has been applied more widely to encompass less technical scientific and medical practices. Klawiter (2008) has argued for a need to address the relationship between medicalization, biosociality and social movements. Referring to women with breast cancer, Klawiter has argued that the development of new forms of biosociality is linked to the rise of a new regime of biomedicalisation. The isolation of the 1970s for women diagnosed with breast cancer was transformed in the late 1980s and 1990s into new forms of biosociality through supportive relationships, social networks, group solidarity and the construction of new collective identities. The development of breast cancer screening programmes constituted healthy women not yet diagnosed with breast cancer as ‘at risk’ and widened the pool of women identifying with the disease.

I have argued that the social groupings established through user involvement activities in the TSSP and SRP cannot be described as an embodied health movement. However, through the enactment of user involvement practices new forms of biosociality or biological citizenship did emerge. The enactment of user involvement policy to encourage patients and the public to engage with healthcare can be considered as a new practice of science and medicine. Thus, implementation of user involvement policy created new forms of biosociality as professionals brought together service users and formed social groupings based on a specific medical classification, in this case stroke. In both the TSSP and the SRP, it was the ‘user groups’ which stroke survivors described being part of in positive terms, due to the forms of support these groups offered and the sense of belonging they created.

However, a number of authors (Fraser 2010;Orsini 2008) suggest we should be cautious about the emancipatory potential of concepts such as biosociality and biological citizenship. They suggest that how citizens interact with each other and with authorities is structured by existing power relations. Thus patients’ ability to challenge biomedical knowledge or science may be attributed to the values attached to particular ways of knowing and the supremacy of scientific or medical knowledge.

Thus a combination of theoretical frameworks such as Lukes’ three dimensional view of power and biological citizenship may help to explain user involvement practices. Lukes (2005) suggests that we ask why things do not happen, theorising that the most insidious use of power is to prevent conflict arising in the first place. If EHM require an element of ‘self-formation’ do the practices of user involvement seek to contain self-organisation? I therefore suggest that whilst user involvement policy seeks the resources of service users, it inhibits their capacity for protest; the policy prevents EHM from forming, but creates a new bureaucratised form of biosociality. I will expand on such avenues for further research in the subsequent, and final, chapter of this thesis.

Chapter 9: Discussion and conclusion

In this study I set out to investigate the policy of service user involvement in service development and heath research focusing on the case of stroke. The key questions I set out to answer were:

- How are the concepts of power and empowerment defined and operationalised in the user involvement literature?
- How was user involvement policy put into practice in two enterprises by professionals charged with it; and how did stroke survivors invited to participate respond?
- Why have stroke survivors been less mobilised as a patient group compared to other patient groups? Why did a stroke embodied health movement not develop?

In this final chapter, I draw together results from the literature review I undertook, and results from my ethnographic research, the analysis of which was informed by Lukes' theoretical framework related to the operation of power in modern democracies, and a framework which conceptualises the link between the emergence of new groups and identities and new practices of science and medicine (biosociality and biological citizenship). First, I consider the results of my research and its value. Second, I reflect on how inferences drawn from the study relate to current debates on user involvement, in particular questions concerning power and empowerment and the roles of citizens in decision-making about health services and research. I then discuss the methodological approach taken in the thesis and discuss the strengths and limitations of the research. Finally, I present further questions this work raises and discuss potential avenues for future research.

9.1. The value of the research

The research reported here explored the implementation of user involvement policy from the perspective of professionals charged with enacting the policy and service users invited to participate in the activities organised as a response to the policy. The research undertaken was empirically novel in terms of the patient group investigated. Situating the research in two separate, but related, enterprises allowed for comparison of policy implementation. The ethnographic approach utilised (rather than the more commonly used interview method), and the theoretical frameworks adopted to understand how power operates within policy implementation, provide further value to the study.

Stroke provided an exemplar to investigate the implementation of user involvement policy. The research focused on two enterprises seeking to implement the policy – a programme of stroke service improvement embedded in the National Health Service (NHS) (Chapter 6) and an academic stroke research programme (Chapter 7). Stroke has not often been the focus of exploration of user involvement policy and practices, with researchers tending to focus on the implementation of user involvement practices in the fields of cancer and mental health. Unlike these two health fields, stroke does not have a well-established history of patient mobilisation and activism, which consequently, led to my interest in understanding why this might be so (Chapter 8).

The research was undertaken using an ethnographic approach entailing participant observation, interviews with key informants - professionals and stroke survivors engaged in the process to implement user involvement policy, and collection of documents. As such, it was conducted over an extended period of time which allowed close examination of how involvement practices evolved in the two separate, but related, enterprises. Other researchers have employed similar methodological approaches to investigate user involvement practices (for example Rutter 2004;Hodge 2005). However, these researchers have taken a more ‘observer’ than ‘participant’ role, primarily conducting non-participant observation of meetings between service users and professionals once user involvement activities have been established.

By contrast, I was able to research the process of policy implementation from the outset. This enabled me to witness, over time, professionals’ interpretation and reinterpretations of Department of Health (DoH) policy as it was implemented. Thus, in Chapter 6, in the case of user involvement in the Transforming Stroke Services Project (TSSP), I argued that aspects of DoH policy concerning the transfer of power from professionals to patients were not as explicitly translated into TSSP documents outlining the ethos of user involvement. Early TSSP documents used metaphors for involvement such as ‘people with stroke in the driving seat’ which might be taken to mean stroke survivors would be given some control over the direction of the project. As user involvement practices were enacted and stroke survivors invited to participate in the TSSP, the ethos of involvement was again reinterpreted as it became apparent that involving stroke survivors throughout the TSSP, as stated in early TSSP documents, was not going to be achievable. Being a participant observer from the outset of policy implementation revealed the lengths professionals had to go to, to encourage stroke survivor participation in the TSSP. This highlighted assumptions inherent in DoH user involvement policy that a group of patients wishing to participate in service development was readily available and that involvement in service development is something which patients' desire.

Despite DoH policy rhetoric for patients to become partners in designing NHS services, the language adopted in TSSP documents generally referred to the *involvement* of stroke survivors in the project rather than stroke survivors having control over the project. Consequently, stroke survivors and professionals in the TSSP remained in their traditional spheres and roles, with TSSP professionals primarily defining the parameters of involvement. TSSP professionals drove the transformation of care, as plans for stroke service improvement had been defined before stroke survivors had been invited to take part. User involvement was not viewed by TSSP professionals nor stroke survivors as a mechanism to transform relationships between patients and professionals and transfer power to patients as indicated in the policy.

A theme emanating from observations of, and interviews with, stroke survivors was that of isolation and a need for 'community'. The isolation stroke survivors discussed with me stemmed from the effects of the stroke but was also compounded by changes in the community where the majority of stroke survivors I met over the course of the research had lived most of their lives, changes in family life, and poor provision of stroke care, particularly once stroke survivors have been discharged from hospital. Initially, it seemed to me, that by providing an opportunity for stroke survivors to come together, participating in user involvement activities began a process whereby their sense of isolation might be reduced. However, the professionalised nature within which user involvement was enacted prevented the creation of a community of stroke survivors beyond that of the meetings of the user groups. User involvement ultimately was not about creating community, but was about individualised engagement between patients and professionals – an extension of policies such as patient centred care where patients are expected to take responsibility for their health and its management (Barnes & Prior 2009).

In Chapter 7, researching policy implementation from the outset using an ethnographic approach similarly enabled observation of how a policy emanating from DoH was interpreted and put into practice by professionals in the Stroke Research Programme (SRP). Observing and participating in the process of implementing stroke survivor involvement allowed for observation of the bringing together of research and 'the researched'. This coming together of these two groups was not always straightforward, particularly as stroke survivors and researchers held conflicting views of the purposes of research.

In the case of the SRP, the requirement on researchers to involve stroke survivors in research was ultimately driven by DoH policy relating to research governance and research funding, rather than an 'ideological ' commitment to user involvement. In contrast to the TSSP, professionals in the SRP (researchers) initially at least, criticised the policy and questioned whether it was realisable. However, at the same time, in the academe the policy was accommodated and user involvement itself was given value by being transformed into an object of research.

As with the TSSP, the implementation of user involvement in the SRP served to maintain boundaries between researchers and the researched as the ‘user group’ was separated from the SRP and researchers, physically and temporally. Experiential knowledge was seen by researchers and even by some stroke survivors as having less value than knowledge produced by experts. Ultimately, in the process of producing scientific knowledge, experiential knowledge had limited value because it was antithetical to the dominant way scientific knowledge is constructed, that is it must be objective, value free. However, experiential knowledge acquired value when it was incorporated into researcher-defined research questions. In this context, experiential knowledge gave these research studies value, allowing researchers to demonstrate their compliance with policy and funder demands.

In Chapter 8, I combined the theoretical frameworks of Lukes’ (2005) three-dimensional view of power and health social movement theory (Brown & Zavestoski 2004) to explore what did not occur. Namely, to understand why a stroke survivor activist movement has failed to develop in the way that survivor movements have arisen and grown in other health fields such as mental health, breast cancer and HIV/AIDS. Drawing on Lukes’ radical view of power, I investigated how patterns of acquiescence might explain the absence or non-occurrence of a stroke survivor activist movement.

User involvement activities implemented in the TSSP and SRP brought stroke survivors together. Through the narration and sharing of stroke stories, stroke survivors were able to create a collective illness identity, the first element of an EHM. However, a politicised illness identity did not develop meaning that the second and third elements of an EHM – challenge to medical knowledge and collaboration with professionals – were not met. Patterns of acquiescence associated with stroke – historically poor quality of stroke care, lack of funding for stroke research, the association of stroke with old age – offer a partial explanation for why a stroke EHM has not developed. User involvement policy further inhibited such a development by impeding self-organisation: while it invited citizen participation, it defined and maintained the boundaries of that participation.

I now turn to my key questions to discuss in greater detail two themes emanating from my research which also form key debates in the user involvement literature:

- Power and empowerment
- The role of citizens in healthcare

9.2. Power and empowerment

At the outset of the research I was struck by the prominence of the concepts of power and empowerment within the user involvement policy and academic literature. In particular, I was interested in the suggestions made by proponents of user involvement that implementation of the policy will lead to a transfer of power from professionals to patients, giving patients a 'voice' in decision-making about publicly funded health services and research. I therefore felt that a theory based on understanding power would be necessary.

Lukes' (2005) radical view of power provided a framework for understanding how power operates and to guide my thinking about how power and empowerment were defined and operationalized in the two enterprises where I conducted my research. This sets my study apart from the majority of the user involvement literature which has neglected to take a theoretical stance on power and in many cases neglected to critically analyse some of the assumptions made about power and how it operates within organisations attempting to implement user involvement policy (see Chapter 2).

Lukes' three-dimensional view of power critiques two earlier views of power as too committed to the study of overt and actual behaviour in decision-making. The one-dimensional view of power is characterised by concrete, observable behaviour in decision-making. The two-dimensional view of power introduces the concept of 'non-decision making' whereby the powerful control the agenda and keep potential issues out of the decision-making process. To these, Lukes adds his third dimension of power, whereby political systems or decision-making within institutions are sustained by the ‘socially structured and culturally patterned behaviour of groups and practices of institutions, which may indeed be manifested by individuals’ inaction’ (Lukes 2005: 26). In this three-dimensional view of power, Lukes points to power as a means of shaping the perceptions and cognitions of others in such a way that they accept their role in the existing order of things. This position moves away from a Weberian perspective of power as the ability of individuals to realise their wills or intentions, to a position where power to control the political agenda and exclude potential issues of interest is seen as a function of collective forces and social arrangements. Thus, power in this perspective may be exercised by individuals or groups, consciously or not, through the shaping of preferences. Furthermore, Lukes’ three-dimensional view of power, in contrast to the one and two dimensions, introduces the idea that power does not have to involve situations of conflict. In fact, Lukes argues that the most insidious exercise of power is to prevent conflict from arising in the first place.

In the case of enactment of user involvement policy in the TSSP (Chapter 6), in the one-dimensional view of power stroke survivors participated in the decision-making process in that they were invited into the decision-making arena, sitting alongside TSSP professionals on decision-making bodies such as the TSSP Management Group. However, at the two-dimensional view of power, service users were not allowed to influence the areas of stroke service improvement the TSSP would address. The areas of service improvement to be addressed had been decided prior to stroke survivors’ involvement in the TSSP. Although stroke survivors' grievances – the lack of physiotherapy provision and problems with transport for those with reduced mobility as a consequence of stroke – were acknowledged by TSSP professionals, developing solutions to these problems were said to be beyond the remit of the TSSP.

This brings us to the three-dimensional view of power and raises the question of why did stroke survivors not challenge the existing order and their role in it? In Chapter 6, I presented some reasons why stroke survivors did not challenge professionals such as the traditional role of the patient not to challenge medical authority and differing values attributed to the experiential knowledge of patients and expert knowledge of health care professionals. The professionalised nature of user involvement practices adopted in the TSSP, such as the use of job descriptions and terms of reference, and encouraging those stroke survivors with experience of serving on committees to participate in the TSSP Management Group also served to convey to stroke survivors how they were expected to behave within the organisation.

The three-dimensional view of power also raises the question why the policy itself went unchallenged by TSSP professionals. Whilst some professionals may have believed stroke survivors were incapable of contributing to certain areas of service improvement, no one ever criticised the need for the policy to be implemented. I suggest that political ideologies implicit in user involvement policy such as New Labour's Third way encompassing notions of egalitarianism, decentralisation of government power, personal responsibility and citizenship (Powell 2000;Rose 2000), made it impossible for professionals to publically speak critically of the policy. To do so would have been tantamount to ethical and moral heresy, implicitly denying the rights and responsibilities of citizens, as taxpayers and users of health services, to have a say in their NHS.

I directly experienced this towards the end of my research when my colleagues and I published an article on user involvement in the TSSP (Fudge *et al.* 2008; see Appendix XIII). Although Debbie (the TSSP manager) and Jackie (service improvement lead with responsibility for user involvement) had read a final draft of the paper and given comments, once the paper had been published I sensed a slight annoyance on their part that the paper was a critique of user involvement which those working within the TSSP had deemed successful. In publishing what I considered to be a balanced critique of user involvement I felt we had broken the unwritten rule of criticising 'user involvement'. This was also reflected in a 'rapid response' to the published article (MacFarlane, *et al.* 2008). The letter suggested that our experience was an exception and our research was interpreted as questioning the benefits of user involvement locally and the effectiveness of user involvement as a national policy.

In the case of the SRP, stroke survivors had a limited role in decision-making. Stroke survivors had some influence on how research was carried out in the SRP, for example data collection, redesigning research ethics forms, but this served to enhance their participation in research rather than representing any decision-making power. Meetings which brought together stroke survivors and stroke researchers were held separately from the main arena where decisions about the kinds of research that would be undertaken in the SRP. Thus at the two-dimensional level power through non-decision making was exercised by determining the arenas stroke survivors could access and the issues which would be discussed in such arenas. Furthermore, the production of a research newsletter for stroke survivors who were participants on the Register provides another example of negative decision-making, or mobilisation of bias, as researchers determined the type of content that could be published in the newsletter.

At the three-dimensional view power was exerted by professionals through Lukes' notion of inertia: stroke survivors were encouraged to generate new research questions based on their experiential knowledge, but professionals did not act on these ideas to transform them into research studies. However, inertia does not fully explain the situation. Not only did researchers fail to act on ideas suggested by stroke survivors but used implementation of user involvement policy to meet their own needs – namely increasing research output through publication. Within the category of researcher, power was exercised to maintain traditional hierarchies of the disciplines. Responsibility for user involvement lay with researchers with a social science background yet the SRP as a whole benefitted from the enactment of the policy in terms of demonstrating compliance with research governance requirements. As with the TSSP, this raises the question why researchers with a social science background have not resisted the responsibility for enacting involvement.

The strength of Lukes' framework is that he added a third dimension to two existing theories of power which allowed unobservable power to be built into analyses of power in empirical contexts. However, Lukes' framework was not based on empirical research. It has been up to others, most notably Gaventa (1982), with his work on power and powerlessness in Appalachia, to demonstrate empirically what Lukes had argued was theoretically possible. Another limitation of Lukes' work is the lack of attention to the place of knowledge in understanding the operation of power. Lukes refers to knowledge in the context of Foucault, but he does not explicitly build knowledge into his framework. In both the TSSP and SRP knowledge was key to understanding stroke survivor participation. Different forms of knowledge (experiential, expert) were valued variously within each enterprise with the effect of keeping people in their place. In the SRP experiential knowledge was not used to influence the research agenda or the type of research questions the SRP would address. The value of experimental knowledge lay with how research was conducted, enabling SRP researchers to demonstrate that research governance and policy requirements were being complied with. In the TSSP, experiential knowledge was only valuable for the non-technical, non-clinical aspects of the project. Therefore, in both enterprises, experiential knowledge was given a place, but not a position which would upset the status quo or usual operating procedures within each organisation.

In both the TSSP and SRP, user involvement was adapted to maintain the status quo; indeed user involvement was used to enhance the institutions by demonstrating policy compliance and being on message with current thinking about the need to enter into dialogue with citizens. Any radical potential inherent within user involvement as a form of patient participation was constrained by the top down and professionalised approach to user involvement policy implementation. This raises the question of why did stroke survivors even bother to get involved? The answer to this questions lies, in the type of people I have identified as being involved – empowered, civic minded and civically engaged prior to their participation – and the fact that many of the participating stroke survivors used the invitation to be involved as a way of addressing their own specific needs, whether this was to meet other stroke survivors, share experiences or access health and social care services.

My research demonstrates that despite implementation of user involvement practices there was little evidence of a 'transfer' of power between patients and professionals. However, this finding rests on the assumption implicit in the policy that power is an entity which can be transferred from one group to another rather than existing through relationships as Lukes, following Foucault argues. I have shown that a more nuanced understanding of power is necessary to grasp the complexities of policy implementation.

A further assumption within the policy literature concerning the transfer of power is that this is something desired by patients and professionals. I observed that whilst the concepts of power and empowerment may appear significant at the level of the policy and for organisations such as the DoH and Involve, for the participants involved in the study these concepts were of less concern.

Whilst empowering patients may have been a wider aim of user involvement policy, in the two enterprises where I observed implementation of the policy, empowering patients was of less concern for professionals than demonstrating compliance to the policy in terms of citizen engagement. The goal of the TSSP was not explicitly to promote patient empowerment as the project was primarily concerned with service development. However, I did often hear TSSP professionals describing the participation of stroke survivors in the TSSP user involvement activities as 'empowering'. These professionals were referring to the empowering nature of involvement through the enhancement of an individual's skills and assertiveness as a result of having been given the opportunity to talk about their experience of stroke services. Empowerment was not defined as a collective matter or a question of increasing access to resources.

In the SRP, patient empowerment was never seen as an objective of involving service users in research. References to patient empowerment feature less frequently in documents relating to involvement in research compared to documents pertaining to involvement in health service development. Stroke survivors were a resource to allow the SRP to demonstrate to research funders and those governing research that they had embraced the ideology of engagement with patients and the public. Stroke survivors were given the opportunity and space to come together to share experiences of stroke and air anxieties about the NHS. Some members of the group described this opportunity as empowering; in particular, one member wrote an article for the research newsletter about the empowering nature of belonging to the research advisory group.

In summary then, at the outset of my research the concepts of power and empowerment seemed to be important, particularly from the perspective of the policy aims. However, as I was engaged in the processes of implementing user involvement policy these concepts had less resonance for those involved. Thus a more useful concept to explain user involvement practices may be that of biological citizens, which I explore next.

9.3. Biological citizens

In Chapter 8 I introduced two conceptual frameworks, embodied health movements (Brown & Zavestoski 2004) and biosociality (Rabinow & Rose 2006) or biological citizenship (Petryna 2002;Rose 2007), to characterise patient mobilisation and activism. Drawing on Lukes' radical view of power, I investigated how patterns of acquiescence might explain the absence or non-occurrence of a stroke survivor activist movement.

Whilst I have argued that a stroke embodied health movement, at this point in time at least, has not developed, I have suggested that through the enactment of user involvement practices new subjectivities and practices have emerged. The enactment of user involvement policy to encourage patients and the public to engage with healthcare can be considered as a new practice of science and medicine. Thus, implementation of user involvement policy created new forms of biosociality or biological citizenship as professionals brought together service users and formed social groupings based on a specific medical diagnosis and classification, in this case stroke. In a similar vein to Rabinow's 'biosociality', Rose and Novas (2005) use the term 'biological citizenship' to refer to the way that ideas of citizenship are linked to biological identities which are individualising and collectivising in nature. The individual active biological citizen keeps herself informed and lives responsibly adjusting diet and lifestyle to maximise health (Whyte 2009). At the same time biological citizenship is created from above by medical and legal authorities who classify people according to their biological identity – for example diabetic, HIV+.

The stroke survivors, who chose to participate in the user involvement activities I observed and helped to establish, can be considered biological citizens. Their identity was formed in part by their decision to identify with their stroke and in part by top down policy directives requiring health care professionals, NHS managers and health researchers to identify and engage with a group of people who fit a biological classification.

I will further argue however, that whilst Rose and Novas note that biosocial groupings – collectivities formed around a biological conception of a shared identity – have a long history of medical activism which predates recent developments in biomedicine and genomics, current forms of biological citizenship formed through user involvement policy directives may be a means for authorities to curtail activism and protest on the part of citizens. As Lukes theorises, the most insidious use of power is to prevent conflict arising in the first place. It could be argued that user involvement policy is designed to impede self-organisation, to invite citizen participation but to define and maintain the boundaries of that participation.

My research therefore warrants a deeper exploration of these concepts of biological citizenship and biosociality to less technological forms of groupings based on a biological identity. Whyte (2009) highlights the benefits of an ethnographic approach to investigating such questions which may reveal those who may wish to exclude themselves from such identities. Through my research I had brief encounters, usually during telephone conversations to invite stroke survivors to participate in stroke service or research development, with people who declined to be identified by the stroke they had had, or who declined to take on a role (whatever that turned out to be in the end) in service and research development.

Further research could investigate how stroke survivors subverted the policy (Barnes & Prior 2009). The user involvement-related activities established in response to the policy gave stroke survivors the opportunity to meet other stroke survivors. This served other needs they had such as the desire to engage civically and interact socially with fellow stroke survivors to share information and experiences. In most cases, meeting the objectives of the policy such as determining the direction of stroke service development and research was a less significant motivation for participation. However, in both the TSSP and the SRP, the enactment of user involvement policy did little to create *new* subjects, in terms of citizens with a sense of civic responsibility. The majority of stroke survivors participating in the TSSP and SRP had already acquired this identity as they were actively in engaged in their local community and were actively interested in the production and maintenance of their own health. The policy ‘failed’ to be implemented due to the large number of stroke survivors on the South London

Stroke Register and those living within Lambeth and Southwark who chose *not* to participate in user involvement activities. These stroke survivors possibly rejected the discourse of ‘responsibility’ in relation to health and health services inherent within user involvement policy on which the status of citizenship is conferred (Barnes & Prior 2009).

9.4. Strengths and limitations of the research

A clear theoretical and methodological base underpins this study. This sets the study apart from previous research in the field, which has either failed to theoretically ground research or critically question assumptions inherent within the policy. Application of an ethnographic approach within health services research context requires different demands of the convention, which I now discuss.

The work provides an empirical account of how user involvement policy was implemented within a specific patient group. Whilst the story of implementation may vary in a different context or health field, how the policy was interpreted by professionals and service uses may not necessarily differ from what I have demonstrated here in this thesis. Therefore the questions I raise through this thesis are applicable more broadly to the policy of user involvement. My literature review (Chapter 2) provided consensus that formal structures of patient participation (whether this be in the form of user involvement policy, as practiced in the UK, or

CBPR, as practiced in north America) limited rather than promoted the involvement of service users in making decisions about health services and health research.

In this study the utilisation of an ethnographic approach concerned situating the research in the contemporary field of health care and research. In contrast to classical anthropological notions of the field as a discrete, bounded, identifiable place the field of my study was multi-sited including national policy on involving patients in health research and service design; NHS and academic enterprises where the policy was implemented; stroke survivors' experience of stroke; and the wider context of lay expertise and challenge to experts. However, a limitation of conducting ethnography in such a setting is that I did not cross the boundaries of research participants' public/private lives (Day 2007). I only participated in and observed activities directly related to user involvement policy implementation. I never participated in participants' lives outside of user involvement-related activities such as a meeting of a user group or work to organise such meetings. This also meant that stroke survivors, and indeed professionals, who did not participate in user involvement-related activities were excluded from the research as my data collection very much focused on the explicit activities of involvement and those people who were connected to them.

The ethnographic approach I have taken is an interpretive one and does not provide the only or most legitimate account but an account that is open to discussion and critique (Savage 2000). Whilst I have attempted in this study to privilege participants' voices, I remain aware of my own influence on the collection, analysis and presentation of data. For example, throughout the research I experienced points of tension which may have had implications for the results of the research. Throughout participant observation and the process of establishing user involvement activities I felt warmth towards the stroke survivors that I met coupled with a belief that people have a right to be involved in research and service development. At the same time I experienced ambivalent feelings towards the policy of user involvement and its inherent assumptions and tokenism.

Throughout the process of participant observation and data collection, I felt I had to take a particular stance on user involvement. In order to gain access to the TSSP and to be able to work closely with Jackie, I felt I had to adopt a positive attitude towards user involvement – that it was morally right for service users to be involved in decisions about services. However, in discussions with Jackie, I was able to express my reservations about the way the policy was promoted and the naive assumptions within the policy which made it hard for professionals to implement the policy, as she too held these conflicting views. Within the SRP, it was necessary to be positive about user involvement in order to encourage other researchers and stroke survivors to participate so that the user involvement could be established within the programme.

Throughout the course of researching and writing this thesis a number of questions have been raised that warrant further research. Below, I outline how future research may continue to add to our understanding of some of the assumptions inherent within user involvement policy.

9.5. Implications of the research and further study

There is concern amongst some researchers and proponents of user involvement for research to demonstrate 'impact' of user involvement in terms of improving health services and research quality (Barber *et al.* Epub;Staniszewska *et al*. 2011;Mockford *et al.* 2012;Barber 2011; Brett *et al.* Epub). To this end, Involve (the advisory body funded by DoH to promote public involvement in NHS, public health and social care research) have established a group, invoNET, specifically to explore the impact or contribution of user involvement in research.

My research has not directly examined policy evaluation in terms of the impact of user involvement on service and research outcomes. Rather, the purpose of my research has been to examine the complex set of relationships at play in policy implementation. However, the results of my research have implications for those researching impact.

There have been calls for the use of randomised controlled trials (RCTs) to provide evidence of impact (Nilsen *et al.* 2006;Boote *et al.* Epub). My research provides evidence of the multiple meanings assigned to user involvement and multiple outputs of involvement. In both chapters 6 and 7, I demonstrated that stroke survivors did not necessarily perceive user involvement practices as being concerned with service improvements or research development. For example, as my research demonstrated, involvement was about a coming together of stroke survivors for support and information. In the case of the SRP, to have a say in research was a secondary driver for attendance. This suggests that identifying the active component and anticipated outcomes of user involvement necessary for undertaking an RCT to provide evidence may be difficult. Other evaluation methods, such as the ethnographic approach utilised here, may be more appropriate for policy evaluation of user involvement as a complex intervention, taking into account factors that may shape and constrain user involvement in health care and research.

In terms of practice, the ethnography presented here suggests that the presumed policy benefits of the policy may not be easily achieved. As a result of the multiple meanings, philosophies and outcomes of involvement, the radical change to health services and research practices desired may not be achievable through implementation of the policy. Greater debate therefore is required amongst those implementing the policy as to why user involvement is desired, what is hoped to be achieved by increasing involvement of service users in the health system, as well as more evidence and critical analysis of the improvements user involvement is said to bring.

My study has shown that a small proportion of the local Lambeth and Southwark stroke population actively participated, raising questions about the type of service user or citizen who decides to participate in activities to improve health services and to have a say in stroke research. As I discussed in Chapter 8, rather than linking the benefits of user involvement practices to health service or research reforms, the user involvement literature tends to present the benefits of user involvement practices as relevant to the individuals who have taken part such as increased confidence and knowledge and gaining skills in new areas (see for example Horrocks *et al.* 2010; Dewar 2005). A recent review by Brett *et al.* (Epub) further confirms the limitations of the evidence base reporting the impact of patient and public involvement in health and social care research.

This raises the question of whether implementation of user involvement may lead to inequalities if only a small group of service users experience the individualised benefits of involvement. Assuming that involvement in service development and research engenders patient empowerment, as the policy literature suggests, certain patient groups, those choosing to participate, may have the opportunity to become empowered whilst others will not. A further question my research raises is whether the benefits of user involvement in terms of patient empowerment are limited to those who decide to participate in involvement initiatives or whether these benefits extend to those who choose not to participate.

As I reported in Chapter 8, Klawiter (2004) argues that the success of an embodied health movement should be measured by how the lives of those with the illness, who have not directly participated in the social movement, have been changed for the better. A future avenue for research would therefore be to focus research efforts on evaluating whether involvement practices bring changes to health services and research outcomes, which benefit all patients, and not just those who choose to actively participate in user involvement activities.

One of the central questions as I embarked on the research concerned how the concepts of power and empowerment are defined and operationalised in the user involvement literature and in the two enterprises where I conducted the research. Most of the user involvement literature fails to question why governments are increasingly encouraging the empowerment of patients in the first place and why it is the responsibility of professionals to achieve this through implementing policies such as user involvement.

Taking a definition of empowerment as one of control over decision-making (the policy literature is concerned with transferring power and control from professionals to patients) ignores structural influences on people’s behaviour which prevents them from becoming empowered. If patient empowerment is indeed a requirement to meet certain goals such as improved individual health and more efficient use of health services, perhaps there needs to be consideration of other forms of empowerment – for example, economic empowerment? Furthermore, implementing user involvement may not be the best mechanism through which to empower patients. As my research has shown user involvement practices are resource intensive, are undertaken by a relatively small number of service users, and those service users who do actively participate are perhaps those who need empowering the least. Future research should therefore question why there is a need to empower patients, and, if the need is justified, to examine effective means to achieve patient empowerment.

Finally, I suggest that future research on user involvement pays attention to other forms of patient participation, such as embodied health movements as mechanisms to achieve health policy objectives concerned with improving services and research quality and outcomes to meet the needs of the wider patient population. In a special issue of the Lancet focusing on HIV/AIDS, Killen *et al.* (2012) and Trapence *et al.* (2012) highlight the achievements of gay and men who have sex with men (MSM) activists in the battle against HIV/AIDS. They note that from the outset of reports of an emerging new disease, activists, working on the principles of 'involvement at every level of decision-making' (Killen *et al*. 2012: 314), were able to collaborate with scientists, bioethicists, statisticians and policy makers to successfully accelerate the pace of research to develop better treatments and improve access to these treatments, reform regulations to speed up therapeutic programmes and allow earlier access to treatments for people unable to participate in clinical trials, and influence health policy to enable access to AIDS prevention, treatment and care. To this end, Killen *et al*. (2012: 314) argue that AIDS activism has 'redefined the potential for trial participants to transform the planning and implementation of clinical research'. Both sets of authors argue that activism stemmed from anger in response to personal danger and government neglect and a realisation that to maintain personal health requires collective mobilisation and action.

Ward and Mullender (1991: 29) suggest that group work lies at the heart of empowerment for the

> experience of being with other people in the same boat can engender strength and new hope where apathy reigned beforehand: a sense of personal responsibility, internalised as self-blame, can find productive new outlets. Alternative explanations and new options for change and improvement can be opened up. The demoralising isolation of private misfortune reinforced by public disinterest or, worse, moral

> condemnation and day-to-day surveillance, can be replaced with a new sense of self-confidence and potency, as well as tangible practical gains which individuals on their own could not contemplate.

This resonates with my research findings whereby stroke survivors emphasised the importance of community and a coming together of stroke survivor to share experiences, and embodied health movement or grassroots activity being more effective in garnering change than the individualised nature of user involvement practices.

9.6. Conclusion

What I have observed through this research is particular to the specific period in time during which the research was conducted. Any radical potential on the part of user involvement policy to transform service and research was dissipated by professionals charged with implementing it. However, the individualised nature of user involvement practices I observed through implementation of the policy may change over time as stroke survivors start to mobilise collectively. The Stroke Research Patients and Family Group, the user group set up as part of user involvement policy implementation in the SRP, is still in existence with over 20 stroke survivors meeting with stroke researchers every six weeks. Whilst most members still resist taking on the role of 'researcher', they have overtime developed a stronger conviction of the value of experiential knowledge in relation to expert knowledge.

For the past two years, the Stroke Association has been organising a UK wide assembly to bring stroke survivors together to have their say on the issues affecting them and pass on these messages to decision-makers and those working in the field of stroke (Stroke Association 2012). However, this attempt to organise and mobilise a movement of stroke survivors, as with user involvement policy, remains in the hands of professionals. It remains to be seen whether stroke as an embodied health movement materialises.

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Appendices

Appendix I: User involvement conferences, seminars, events.

invoNET[40] workshop: Researching public involvement in research, London, March 2006

Involve conference: People in Research, Hertfordshire, September 2006

invoNET workshop: How to measure the impact of public involvement on health and social care research processes and outcomes, London, February 2007

South East Stroke Research Network Annual Meeting, London, May 2007

Authenticity to Action conference: Involving Service Users and Carers in Higher Education, Lancaster, November 2007

Health Services Research Network/NHS Confederation Autumn meeting: 'Methodological issues in researching complex interventions', London, October 2007

National Institute for Health Research conference, 2010

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[40] invoNET is a network of people working to build evidence, knowledge and learning about public involvement in NHS, public health and social care research. invoNET is a collaboration between INVOLVE and Worthing and Southlands Hospitals NHS Trust. Network members include researchers, service users, carers, research funders, academics and health and social care practitioners.

Appendix II: Interview topic guide – TSSP non-participating stroke survivors

About your stroke…

How long ago was your stroke? When did you have your stroke?

How are you doing now? Have you recovered from your stroke?

Can you tell me a bit about your work or family life before your stroke? What did you do before your stroke?

And how about now? What do you do now?

Are you involved in any things like clubs, hobbies, committees, groups etc?

About the stroke get-together...

How did you hear about the stroke get-together?

Letter? Do you know who sent you the letter? Transforming Stroke Service Project? Stroke register?A group you go to?

Why did you attend the get-together?

What did you think was the point of the get-together? What did you think was the purpose of the get-together?

Please give the reasons why you were not able to participate further in the stroke project.

If needed, explain that the government and the NHS are keen for the public and patients (or people who use services) to be involved in making decisions about how to improve services.

What do you understand by 'user involvement' in the NHS?

What do you understand by people who have experience of stroke working with people in the NHS to improve services?

What do you think about projects which ask patients and other people to become involved to improve stroke services?

Do you think people know enough to contribute to improving stroke services?

Do you think people have enough power and influence to improve stroke services?

Appendix III: Interview topic guide – TSSP participating stroke survivors

About your stroke

How long ago did you have your stroke? What happened when you had your stroke?

How are you now? How has the stroke affected your life now?

What did you think of the treatment and service you got for your stroke from doctors, NHS?

A lot of people complain about the state of the NHS – what do you think?

Whose responsibility do you think it is to try to improve the NHS and improve services for people who have had a stroke? Ordinary people?

Life before your stroke

What did you do before your stroke (work/family life)?

What do you do now?

Are you involved in any activities, hobbies, committees?

The Transforming Stroke Services Project

How did you hear about the TSSP?

Which parts of the project have you taken part in so far?

What were your reasons for taking part in the project/peer support/training/long-term support?

What sort of things have you been doing in the project?

How have you found being part of the project? How do you find the meetings? How do you see your role in the project?

Impacts

Do you think that the Transforming Stroke Services Project will change things for people who have strokes? In what way?

How do you think the stroke project is benefiting from having people like you, who have experience of stroke, taking part in it?

Do you feel that the other people in the project listen to you and understand your point of view?

Do you think that people on the stroke project are interested in your ideas and your experience of stroke?

How are your experience and ideas are influencing the way the project runs?

Do you think you have enough power and influence to change the way the stroke project works/ what the stroke project does?

Taking part – facilitators/inhibitors

So far, how easy or difficult has it been for you to be part of the Transforming Stroke Services Project – in terms of attending meetings, contributing to meetings, speaking at meetings?

What are the things that have made it easier for you to come along to meetings and take part?

What are the things which make it difficult for you to attend the meetings/ put you off coming to the meetings?

Are there things which the people on the stroke project could do differently which would make it easier for you to take part?

What have been the positive things for you taking part in the stroke project? What do you get out of taking part?

Have there been any negative things?

Do you think experience of having a stroke is enough to do what you've been doing or do you think you bring other skills from your life to the project?

Appendix IV: Interview topic guide – TSSP professionals

Background

What is your background to user involvement?

How have you come to be working in user involvement roles?

Why are you interested in working with service users in this way?

User involvement policy

Why do you think the government/department of health is demanding that health service providers involve service users in the development of services?

Involving stroke survivors in the TSSP

What are the different ways that people with stroke have been involved in the TSSP?

Barriers to involving users

Facilitators to involving users

Implementing user involvement throughout the TSSP

Why do you think that user involvement has been used so far only in certain areas of the project?

Do you think that there are areas of the project that are better suited to involving people with stroke than others? Why?

What are the barriers to implementing user involvement throughout the TSSP?

Impact

What impact do you think users are having/have had on the TSSP?

What impact do you think users are having/have had on improving stroke services in Lambeth and Southwark?

What do you think the TSSP, people working in stroke services have learnt from stroke service users involved in the project?

Other impacts/benefits of user involvement?

Appendix V: Interview topic guide – SRPFG group discussion

Why did you decide to join the group?

What do you think about the group?

Purpose of the group?

Positive and negative aspects of being part of the group?

What is your role in the group?

Do you feel you can contribute? Are there times when you feel you can't contribute? Do you feel your contributions are valued?

What are the things that have made it easier for you to come along to meetings and take part?

What are the things which make it difficult for you to attend the meetings/ put you off coming to the SRPFG?

How well do you think the researchers prepared you to be part of the group?

Are there things which the researchers could do differently which would make it easier for you to take part?

What skills do you think you need to be a member of the group?

What do you think the group has achieved?

How effective do you think the group has been?

Making sure the views of people with stroke are included in the KCL stroke research

Do you think you have been able to change the way researchers think about people who have had a stroke and their needs?

How do you think the stroke researchers benefit from having people like you, who have experience of stroke, advising them on research projects?

Has being a member of the group changed things for you?

Made a difference to your health?

Helped you to access services? Information about stroke?

Given you confidence to join other groups, be active in your community, feel more control over your own life?

Allowed you to express your views? Has being a member helped you to express your views in other areas of your life?

In our first newsletter one member wrote that the SRPFG and newsletter will ‘provide a voice’, ‘empowering stroke victims and their carers’. What do people think about this? Why do people with stroke need empowering? How should they be empowered?

Your views on stroke research

Has being a member of the group changed your views on stroke research?

In what way?

How should we run the group in the future?

Planning content of meetings

Chairing meetings

Administration of group – meeting summary, sending out letters, calling people about meetings

Recruiting new members? Seeking views from the wider South London Stroke Register group?

Appendix VI: Interview topic guide – SRP stroke survivors

About your stroke

How long ago did you have your stroke? What happened when you had your stroke?

How are you now? How has the stroke affected your life now?

What did you think of the treatment and service you got for your stroke from doctors, NHS?

What did you do before your stroke (work/family life)?

What do you do now?

Are you involved in any activities, hobbies, and committees?

Stroke Research Patients and Family Group

What do you think the purpose of the group is?

How have you found being part of the group? What have been positive and negative aspects of being part of the group?

What is your role in the group?

Do you feel you can contribute? Are there times when you feel you can't contribute? Do you feel your contributions are valued?

What skills do you think you need to be a member of the group?

Who do you represent?

Impact of the group

What do you think the group has achieved?

Has being a member of the group changed things for you?

Has it made a difference to your health?

Has it helped you to access services? Information about stroke?

Has the group given you confidence to join other groups, be active in your community, feel more control over your own life?

Has being a member allowed you to express your views? Has being a member helped you to express your views in other areas of your life?

Explain that in our first newsletter one member wrote that the SRPFG and newsletter will 'provide a voice', 'empowering stroke victims and their carers'. What do people think about this? Why do people with stroke need empowering? How should they be empowered?

How effective do you think the group has been?

Making sure the views of people with stroke are included in the KCL stroke research

Do you think you have been able to change the way researchers think about people who have had a stroke and their needs?

How do you think the stroke researchers benefit from having people like you, who have experience of stroke, advising them on research projects?

Taking part – facilitators/inhibitors

So far, how easy or difficult has it been for you to be part of the SRPFG – in terms of attending meetings, contributing to meetings, speaking at meetings?

What are the things that have made it easier for you to come along to meetings and take part?

What are the things which make it difficult for you to attend the meetings/ put you off coming to the SRPFG?

How well do you think the researchers prepared you to be part of the group?

Are there things which the researchers could do differently which would make it easier for you to take part?

Appendix VII: Interview topic guide – SRP researchers

Can you tell me a bit about your background, how you got into research, why you've chosen a career in research?

Policy – why do you think as researchers we are encouraged to involve research participants more closely in our research? Did you have experience of involvement prior to this job?

What do you think the purpose of the SRPFG is?

Why did you decide to discuss your research with the user group?

What were your expectations of the group and how they might be able to contribute to your research?

Was this achieved through your actual visit to the group? If not, why not?

What were the benefits, if any, of discussing your research with the user group?

Were there any problems or disadvantages?

What contribution could the user group make that could not be gained from discussions with researchers?

How well prepared did you feel you were for interacting and discussing your research with the user group?

Has your experience of the user group changed the way you think about and conduct research?

In general do you have any ideas about things we could do to increase engagement and interaction between members of the research team and people with stroke?

Additional questions specific to the Head of Department

User involvement policy

Your opinion of the policy

How you’ve seen the policy being introduced over time.

Why you think researchers are being encouraged to involve patients and the public more closely in the research that they do.

What are the priorities of the research team? How does user involvement fit with these?

What influence, if any, has the research user group had on the stroke research team?

Appendix VIII: Participant information sheet

Involving people who have had strokes and their families in stroke research: an evaluation.

Can you help with a research project?

The research is being done at King’s College London.

Chris McKevitt and **Nina Fudge** are the researchers working on the project.

Sally Byng, Tony Rudd and Charles Wolfe are also working on the project.

This **information book** tells you **about** the **research** and **how** you can **help**.

Please take time to **read** the following **information** carefully and **discuss** it **with others** if you wish.

Thank you for reading this.

What is the research project about?

The **research** is **about** how to **involve people** who have had a stroke and their family members in **research**.

What helps people with stroke to take part in research?

What gets in the way?

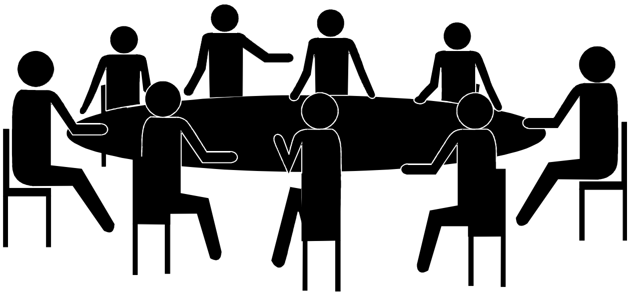
What helps family members of people with stroke to take part in research?

What gets in the way?

Does involving people who live with stroke improve the quality of research?

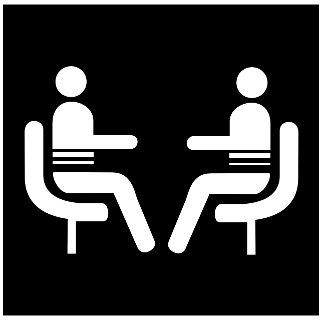
What will the researchers do?

Nina will **observe** what happens in the Stroke Research Team meetings.

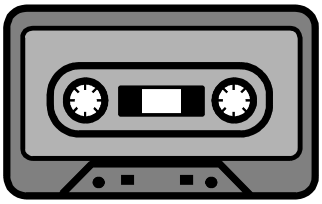


Nina will **take notes** about what happens.

Nina will **interview** people who have had a stroke, their family members and researchers to find out about their **experience** of being involved in stroke research.



Nina will **record** the **interview** on an **audio tape**. You can **stop** the interview at any time.



The **interviews** will last for about **one hour**.

Your **name** will **not** be **used**.

Everything you say will be **confidential**.

Why is this research important?

The project will show researchers the **best ways** to **involve people** who have had a stroke in **research projects**.

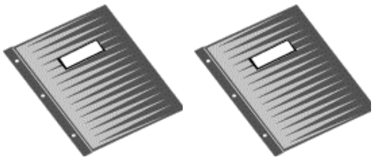
The project will show how **people** who have had a stroke can **change** the way **research projects** are **done**.

The project will **help researchers** who want to **involve people** who have had strokes in **research projects** in the **future**.

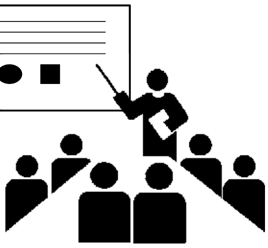
What will happen to the research?

A **summary** of the **results** will be **sent** to **you**

The **research** will be **published** in **reports**.



The **research** will be used for **teaching** or at **conferences**.



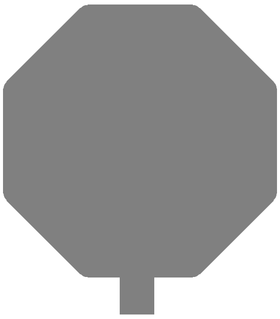
The **results** will help **future** researchers **develop ways** of **involving people** who live with stroke in **research projects**.

Do you have to take part?

- You are **free** to decide whether or not to **take part** in the research.

- If you **agree** to take part you need to **answer** some **questions** and **sign** the **consent form**.

- You are **free** to **stop** the **research** at anytime and you do not have to give a reason why.



Any questions?

If you have any questions talk to **Nina**

✉

Nina Fudge
7th Floor Capital House
42 Weston Street
London SE1 3QD

☎

020 7848 6644

🖥

nina.fudge@kcl.ac.uk

St Thomas' Hospital Research Ethics Committee
CONSENT FORM FOR PARTICIPATION IN RESEARCH PROJECTS AND CLINICAL TRIALS
Ethics Committee code no.: 04/Q0702/108 Date: 26/01/2012
Principal investigator: Dr C McKevitt
Other investigators: Ms N Fudge, Prof S Byng, Dr A Rudd, Prof C Wolfe

Patient information sheet and consent form v2 RESEARCH

Consent Form

Involving people who have had strokes and their families in research: an evaluation

	👍	👎
I have seen the information book about the research	Yes ☐	No ☐
I have talked with Nina about the research	Yes ☐	No ☐
Nina has answered my questions	Yes ☐	No ☐
I understand what is involved	Yes ☐	No ☐

Observation of research meetings	👍	👎
I understand that Nina will come to meetings, watch what happens and take notes.	Yes ☐	No ☐
I understand that my name will not be used.	Yes ☐	No ☐

Interviews

👍 👎

I agree to be interviewed Yes ☐ No ☐

I agree to be recorded on audio tape Yes ☐ No ☐

I understand that I can stop the interview Yes ☐ No ☐

I understand that my name will not be used Yes ☐ No ☐

If you agree to take part in this research please could you sign below:

Name ………………………………………………………………..

Signed (volunteer)……………………………… Date …………..

Witness (where appropriate)………………………… Date …………..

Signed (researcher)…………………………….. Date …………..

St Thomas' Hospital Research Ethics Committee
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Patient information sheet and consent form v2 RESEARCH

Appendix IX: An Invitation to join the Stroke User Group

An invitation to join the Stroke Research Patients and Family Group

You, or someone in your family, are part of a register of people in South London who have had a stroke.

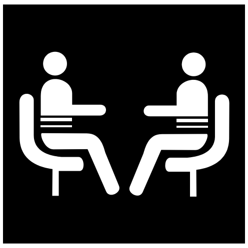
The South London Stroke Register is run by a team of researchers from King's College London, based in the Guy's, King's and St Thomas' School of Medicine.

We would like to invite people who have had strokes and their relatives to work with us.

This is to make sure that stroke research is relevant to the people who are supposed to benefit from it.

Stroke research in South London

As you know, a fieldworker from the research team comes to see you once a year and asks you questions about your stroke.



The answers that everybody gives are used to help understand:

How many people in South London have strokes?

What services do people who have had a stroke need?

How many people who have a stroke have another stroke?

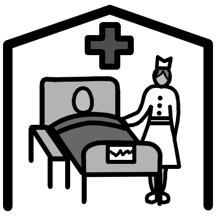
How do strokes affect patients and their families in the short-term and the long-term?

What are the different causes of stroke?

How well are the needs of people who have a stroke being met?

This information helps to improve:

medical care



follow-up care after stroke

social services

We would like to hear what you think about stroke research in South London.

Please come to a meeting on:

Tuesday 25th October 2005

2:00 – 4:00 pm

Greenwood Theatre, 55 Weston Street, London Bridge,
London SE1 3RA

- You will hear about the research.
- We will listen to what you think of the research.
- We will listen to your ideas.
- As a group we will talk about the different ways that you can work with us to make stroke research relevant to people who have had a stroke.

- We will provide transport and expenses if you need help getting to the meeting.

- We will provide refreshments at the meeting.

Who can come to the meeting?

- Anyone who has had a stroke and is on the South London Stroke Register.
- A relative or friend of someone who has had a stroke and who is on the South London Stroke Register.

Interested but can’t come to the meeting?

Please contact Nina Fudge to discuss other ways that you can take part in stroke research.

Contact information

Please let Nina Fudge know if you wish to attend the meeting (you can use the reply slip and pre-paid envelope).

✉

Nina Fudge
7th Floor Capital House
42 Weston Street
London SE1 3QD

☎

020 7848 6644

💻

nina.fudge@kcl.ac.uk

KING’S College LONDON
University of London

The South London Stroke Register
Guy’s, King’s and St Thomas’ School of Medicine
King’s College London

Appendix X: Participants – Transforming Stroke Services Project

Pseudonym	Description and role in TSSP
Anita	Stroke survivor who attended the training to become a member of the TSSP management group. However, after attending a couple of TSSP management group meetings she decided not to participate further.
Arthur	Stroke survivor who attended the first stroke get-together but declined to participate further in the TSSP
Carmen	Stroke survivor who was a regular member of the Training Health Care Professionals user group and through that became involved in organising and speaking at 'Stroke raising awareness events' at local GP practices.
Cynthia	Attended the first stroke get-together as a carer for her friend who had had a stroke but declined to participate further in the TSSP
Debbie	TSSP manager
Helena	General Practitioner seconded to TSSP
Irene	Carer involved in the information group and peer support.
Jackie	Service improvement facilitator responsible for user involvement in the TSSP
Jim	Stroke survivor involved in both the TSSP and SRP
Karen	Transformation Project Director
Kartik	Stroke survivor
Margaret	Stroke Nurse Specialist at local stroke unit and member of User Involvement Working Group
Mary	Employee of a communication disability charity seconded to the TSSP
Maureen	Stroke survivor who attended the first stroke get-together but declined to participate further in the TSSP
Mr and Mrs Todd	Stroke survivors who attended the first stroke get-together but declined to participate further in the TSSP
Mrs James	Wife of a stroke survivor
Olive	Stroke survivor who attended the first stroke get-together but declined to participate further in the TSSP
Pam	Wife of a stroke survivor, Pam attended the first stroke get-together and meetings of the information group for about four months until she herself became seriously ill.

Phyllis	Considered herself as ‘at risk’ of stroke. Became involved in the TSSP when she attended with her friend, Carmen, who had had a stroke but who was not confident enough to attend TSSP user group meetings on her own.
Ruby	Stroke survivor who attended the first stroke get-together but declined to participate further in the TSSP
Sarah	Administrator with the TSSP who later became responsible for developing stroke information provision and working on this with stroke survivors.
Sharon	Community physiotherapist and member of the User Involvement Working Group
Simon	Service improvement facilitator responsible for improving acute stroke services in the TSSP
Steve	Adult son of a stroke survivor who attended one of the first stroke get-togethers but declined to participate further in the TSSP
William	Husband of a stroke survivor involved in both the TSSP and SRP

Appendix XI: Participants – Stroke Research Programme

Pseudonym	Description and role in SRP
Anthony	Stroke survivor
Archie	Stroke survivor
Betsy	Betsy was on the stroke register but in an interview with me revealed that she had not in fact had a stroke and had been told by hospital doctors that she had just had a serious fall.
Carol	Anthony's wife
Catharine	Stroke survivor
Derin	Researcher
Jim	Stroke survivor involved in both the TSSP and SRP
Joan	Stroke survivor
Lily	Stroke survivor
Lucy	Researcher
Michael	Stroke survivor
Marian	Stroke survivor
Pauline	Stroke survivor
Professor Brooks	Head of Stroke Research Programme
Robert	Stroke survivor
The PI	Principal Investigator on the project to establish and evaluate patient and family participation in stroke research and stroke service development, out of which this thesis was developed. Additionally, the PI was my PhD supervisor.
Timothy	Stroke survivor
William	Husband of a stroke survivor involved in both the TSSP and SRP
Zoë	Researcher

Appendix XII: Forward newsletter issue 1

Issue 1
June 2006

Guy's and St Thomas' NHS
NHS Foundation Trust

KING'S College LONDON
University of London

FORWARD

News from the South London Stroke Register

WELCOME TO *FORWARD*

This is the first ever issue of **FORWARD**, bringing you news from the **South London Stroke Register**. **FORWARD** is for people who have had a stroke (and their families) who are part of the South London Stroke Register. **FORWARD** is produced by stroke register researchers and members of the Stroke Research Patients and Family Group.

The purpose of this newsletter is to tell you about the results of the research that we are doing, with your help, to try to find out more about stroke and how we can improve stroke care.

Your views and contributions are essential for the success of the newsletter so please get in touch with us if you have any comments about the newsletter or ideas and suggestions for future issues. Please contact:

Nina Fudge (tel: 020 7848 6644) or **Chris McKevitt** (tel: 020 7848 6628)

Address: FORWARD, The South London Stroke Register, 7th Floor Capital House, 42 Weston Street, London SE1 3QD

Email: stroke-register@kcl.ac.uk

Contents

Message from Dr Tony Rudd

Consultant Stroke Physician, Mark Ward, Guy's and St Thomas' NHS Foundation Trust

Not only is this the first newsletter for South London Stroke Register participants but I suspect it is the first newsletter of its kind ever. Without the willing participation of people who have had a stroke, research would be impossible and we would never make any progress in improving the treatments for stroke. This newsletter describes some of the important results from the research in South London over the last 10 years. I think you can all be very proud that your efforts have made a real difference to the way that stroke care is delivered. In this issue of FORWARD you can read

Dr Tony Rudd...Cont.

summaries of three studies we have done.

We very much hope that South London Stroke Register participants will help us to develop the research studies of the future, making sure that the questions that are asked are important, not just to the scientists but to stroke survivors as well.

A Rudd

Everything you wanted to know about the South London Stroke Register

What is it?
The South London Stroke Register is a record of everyone who has had a stroke in the defined Register area, the northern wards of Lambeth and Southwark. The Register has been going since 1995, and there are now over 3,000 people registered.

The South London Stroke Register is unique - it is the largest and longest running stroke register in the world.

Who runs the Register?
The Register is run by the stroke research team in the Department of Public Health Sciences in the Medical School at King's College London. We are based at Guy's Hospital and there are about 18 researchers in the team, including fieldworkers, doctors, health economists, social scientists, statisticians and data analysts.

Why was the Register set up?
The Register was first set up to find out how many people were having strokes and if this number was going up or going down or staying the same. This information was important so that the NHS and the Department of Health could plan for services that are needed by people who have a stroke.

Since then we have used the Register to answer questions such as:

- What happens to people 3 months, 1 year, 3 years or 10 years after their stroke?
- Do people who have a stroke always get the care they need?
- Why do some people seem to do better than others after a stroke?

If we can answer questions like these, we can help to plan care for the future and improve the care that people are getting today. The information we collect for the Register will help us answer questions like these. That's why the information you provide us with is so important.

What information does the Register collect?
Once you agree to be part of the Register one of the researchers asks you information at the time of your stroke, 3 months after your stroke, 12 months after your stroke and then every year after that. We collect information about you (age, sex, ethnic group); about

The Stroke Research Team

your health (blood pressure, cholesterol, diabetes); about the type of stroke you had (using the results from your tests); and about the care that you received (in hospital, out-patient, GP, social services etc).

How does the Register find out when someone has had a stroke?

We work with doctors and nurses in the local hospitals where people might go after a stroke. But we also need to include people who have a stroke but aren't admitted to hospital. So we are also in contact with all the GPs in our study area.

What happens to the information?

The information you give us is pooled with information from everyone else on the Register and stored on computer. We do not keep your personal details (name and address) with this pooled information. We then use this information to carry out our research.

RESEARCH UPDATE

Highlights of research findings from the South London Stroke Register

Stroke researchers at King's College London have been carrying out research into stroke and stroke services for 10 years. In this issue we present findings from three studies.

How common is stroke in south London?

One of the first questions we wanted to answer with the South London Stroke Register was how many people were having strokes in south London and how common stroke is among different groups of people living in our area - younger/older, white/black, poorer/richer. After two years visiting people on the Register we had collected enough information to answer these questions.

We found that:

- About 1 in 500 people in south London will have a stroke each year
- The risk of having a stroke increases dramatically with age
- Stroke is more common in men than women
- Stroke is more common in poorer people compared to richer people
- Black Caribbean and African people are twice as likely to have a stroke compared to white people
- Black Caribbean and African people tend to have a stroke ten years younger than white people

This study was published in one of the most important medical publications in the world - the British Medical Journal. The study highlighted the need to do more to prevent strokes happening and to plan care for those who do go on to have a stroke.

Want to know more? This study was published as:

Stewart J, Dundas R, Howard R, Rudd A, Wolfe CDA. Ethnic differences in incidence of stroke: prospective study with stroke register. British Medical Journal 1999;318:967-971.

You can find the paper on the BMJ website:

http://bmj.bmjjournals.com

Stroke Research Patients and Family Group

In October 2005 researchers from the South London Stroke Register invited Register participants to a meeting to discuss how we could work together on stroke research. As a result of this first meeting a group called the Stroke Research Patients and Family Group was set up. The group is for people who have had a stroke or for friends and relatives of someone who has had a stroke and who are interested in stroke research. The group meets every six weeks to hear about and discuss stroke research, advise stroke researchers about conducting research, develop ideas for new stroke research and carry out research projects. Here one member, Elizabeth Mitchell, describes her experience of joining the group:

"The room was dark with a low ceiling but had the redeeming advantage of enabling all the invited members of the Stroke Research Patients and Family Group, including two wheel chairs, to be seated around its enormous boardroom-style table. The seating arrangements enabled Chris and Nina, the professional researchers running the project, to create a very supportive interactive circle.

The group members were all invited to attend after they had been interviewed in their own homes as part of the Stroke Register Research tracking programme described elsewhere in this newsletter, to involve users of the NHS services to express their views on how the trust might identify the best way of meeting the needs of stroke victims.

Although, outwardly calm, I was in a highly charged emotional state for many weeks after learning I had suffered a stroke and the new challenges it presented. It was with a sense of unreality that I first went along to the group. I had a vague notion of wanting to gain information, information, information, to paraphrase our nation's leader, and to gain some autonomy over my own life in this novel situation.

We learned that there are several kinds of stroke leaving patients with a wide spectrum of disabilities. I found comfort in sharing experiences in the unconditionally supportive accepting climate of the group, created very skilfully by the professionals Chris and Nina. Everyone was encouraged to contribute. I emphasise this because in listening to others I was able to articulate many of my own needs.

> **“I found comfort in sharing experiences in the unconditionally supportive accepting climate of the group... Everyone was encouraged to contribute.”**

One wheelchair-bound gentleman’s wife seemed to meet the challenge of caring for her husband with an intuitive knowledge of his needs that seemed to me to exemplify the Aristotelian flourishing life, finding within herself talents and skills she might have not realised had she not been presented with such a huge challenge. I was reminded of Patricia Neal, the film star, who, after a stroke went on to recover and resume her career with intelligent **t l c**. Some of us only find our strengths when life demands it of us.

Another lady with a very strong personality and sense of humour had her first stroke sixteen years ago. She had navigated her way around the various services and amused us with humorous anecdotes of their successes and shortfalls.

The story was told of the daughter who had taken time off from her job to nurse her mother. This highlighted the impact that stroke can have on families that is clearly not recognised enough. The most heartening thing for me was that they all seemed to have recovered so much from their initial disabilities.

Listening to the researchers, Chris and Nina, and the very diverse and interesting group of men and women who shared this life changing experience helped me understand how the Stroke Register group could be a very useful forum for the exchange of information and sharing solutions. A further possibility posited was the idea of researching the extra costs of stroke to individuals and their families.

Lots of anecdotal information was exchanged on how to help oneself. When the idea of a newsletter was proposed as a way of reaching everyone on the register the group was delighted. It would provide a two-way dialogue for all stroke users of the NHS services in the Trust area. In a discussion on what format it might take it was agreed it should start small with input from the professionals and a questions and letters page. It could widen at a stroke (forgive the pun) enormously the number of people getting professional information, provide a forum for their concerns and report their own strategies for living with stroke, creating a voice in the wider society, and ultimately, through the medium of the newsletter, empowering stroke victims and their carers.

Some comments from other people who attend the group:

"We are all able to sit around the table as if it was someone's front room. I feel good, I think if we go on as we are we will be able to get back the things we are putting in with the comments we all make"

"I am interested in meeting stroke sufferers and how they got over their difficulties"

"I enjoy meeting other people who have had strokes and their carers to hear of their experiences. I feel lucky to have survived my stroke and would like to help others"

If you would like to attend the next meeting of the group please contact Nina Fudge on 020 7848 6644 or write to her at the South London Stroke Register, 7th Floor Capital House, 42 Weston Street, London SE1 3QD.

Quote of the issue

Heard on Radio 4...."**An age of dignity is one that gives dignity to age.**"

RESEARCH UPDATE

Highlights of research findings from the South London Stroke Register

Stroke in south London - How do we compare to other European cities?

Over the last 15 years we have done some research to find out how the situation in south London compares to other places in Europe. When we started this work we knew from other studies that the chances of dying from stroke were very different around the world but it wasn't clear why. Was it because of the type of care people get in different settings? The answers to this question are not straightforward!

The first study we carried out looked at the types of care provided in different countries. Stroke services turned out to be dramatically different across Europe. In certain countries - including England and Eastern European centres - there were no specialist stroke services really. Patients were either not being treated in hospital or being treated in a general medical ward. In other countries, like Germany and Denmark, there were very well developed stroke units. On the other hand, patients in England got good rehabilitation services compared to patients in Italy and Germany, for example.

Our research also showed that there were important differences in the chances of dying from a first stroke, regardless of differences in the patients' age, circumstances or severity of the stroke. People in England tended to have a higher chance of dying or being disabled after their stroke than in central Europe. This research highlighted - perhaps for the first time - that there is a problem with the quality of our stroke services compared to some other European centres. The research showed that we have something to learn from those centres where there is better care and better results for the person who has a stroke. We are currently continuing our joint research with partners in other European centres.

Want to know more? This study was published as:
Wolfe CDA, Tilling K, Beech R, Rudd AG. Variations in case fatality and dependency from stroke in western and central Europe. Stroke 1999;30:350-356.

Your view

This section is for readers of FORWARD to share experiences or comments about strokes, stroke research and articles featured in previous issues. If you have a question or comment that you would like published please write to:

FORWARD
The South London Stroke Register
7th Floor Capital House
42 Weston Street
London SE1 3QD

Or email:
stroke-register@kcl.ac.uk

Letters may be edited and unfortunately we are not able to publish every letter we receive.

Dear Editor,

Congratulations on launching a newsletter for stroke patients. I'd like to ask a question about the advice given to dementia sufferers of all kinds to learn another language to enhance brain function. Is there any kind of language learning programme aimed at overcoming the specific problems of stroke victims? In the current competitive world of education with its targets and league tables could a programme be created that takes account of the special needs of stroke?

May your project go from strength to strength.

Best wishes,
Kathleen

Some speech and language therapists specialise in the needs of people with communication difficulties after stroke. The Royal College of Physicians guidelines for stroke recommended that people with communication disabilities receive speech and language therapy for between 2 and 8 hours per week. In long-term cases a period of speech and language therapy intervention, including group communication treatment should be considered.

Dear Editor,

I suffered a stroke in November 1997 and after a long time in three different hospitals I was discharged to Southwark Park Nursing Home. I had to go into the home as I was not well enough to go back home to my family. Although some of the cost of my stay was paid by Social Services my family had to pay a lot of money. When my sister had visited me in hospital she asked a nurse why wasn't I having any physio and she was told that I would never walk again!

I spent all day in a wheelchair and the only way I could get out of it was with a carer using a hoist.

After I had been there for about a year I was referred to St Thomas' Hospital for physio. I was lucky to meet Ken Cutting who doesn't have the word can't in his vocabulary. Three days a week I was taken in my wheelchair by ambulance to have physio to try to straighten my hamstrings which had shortened. I would be helped out of my wheelchair onto a tilt board and have my legs strapped down and then stood upright. This would be repeated several times. It was so painful but I used to look forward to it as Ken was convinced he could help me. Eventually he got me walking on crutches. When he had done as much as he could he contacted my rehabilitation doctor who arranged for me to have an operation at Guy's Hospital to lengthen my hamstrings.
Once I went home a physio came to see me and it was a big day when we walked round the corner for a coffee! She introduced me to the gym at Peckham Pulse where I still go twice a week.

The next big step was getting my driving license back which took quite a long while due to the inefficiency of the DVLA. I can now drive to see my son and daughter and their families in New Ash Green.

I have become a governor at a Primary School where I also go one afternoon a week to help children with their reading.

But for Ken Cutting I would still be sitting in a wheelchair. I sometimes get the impression that in the medical world physios are not given the credit they deserve.

Obviously having the support of my family has made a big difference to my recovery.

Dave

Dear Editor,

The age at which people have stroke appears to be dropping. If this is correct are the reasons known? If it is 'lifestyle' how do we get the message across?

Harry and Dorothy

Research shows that the average age that people have a stroke is not going down. Strokes can happen at any age, but the risk of having a stroke increases as you get older. As the number of older people in our population increases then we are likely to see an increase in the number of strokes. 'Lifestyle' (diet, smoking, exercise) can influence the chance of someone having a stroke. The Department of Health's new strategy for stroke is going to develop a public awareness campaign.

RESEARCH UPDATE

Highlights of research findings from the South London Stroke Register

THE EARLY DISCHARGE STUDY

Research in south London in the mid 1990s had shown that patients who were admitted to hospital after their stroke stayed there, on average, for 6 weeks. However, they tended to get little rehabilitation therapy while in hospital and when they were sent home they got even less. So we did a study to see whether it would be better to send people home from hospital early - but with the support of a team of therapists to provide rehabilitation at home. We used the South London Stroke Register to follow people up in the course of the study.

The study showed that it was possible to discharge people from hospital early and that with the proper rehabilitation care at home people could do better. On average the scheme reduced the time in hospital by a week and increased the percentage of people who were independent after their stroke. This type of care - known as early supported discharge - has now been tried out in 11 other centres in Britain and elsewhere. In general the same good results have been found. This type of care is now regarded nationally as good practice.

Want to know more? This study was published as: Rudd AG, Wolfe CDA, Tilling K, Beech R. Randomised controlled trial to evaluate early discharge scheme for patients with stroke. British Medical Journal 1997;315:1039-1044.

You can find the paper on the BMJ website: http://bmj.bmjjournals.com

@ Receive the newsletter by email

If you would prefer to receive this newsletter by email please send your email address to: **stroke-register@kcl.ac.uk**

This newsletter is also available on tape. If you would like a taped version please let us know.

Appendix XIII: Publications arising from this thesis

Peer reviewed journal articles:

McKevitt C, Fudge N, Wolfe C. 2010. What is involvement in research and what does it achieve? Reflections on a pilot study of the personal costs of stroke. *Health Expectations*, 13(1) 86-94.

Fudge N, Wolfe CDA, McKevitt C. 2008. Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal*, 336(7639) 313-317.

Fudge N, Wolfe CDA, McKevitt C. 2007. Involving older people in health research. *Age and Ageing*, 36 492-500.

Published abstracts:

McKevitt C, Fudge N, Sriskantharajah A, Coshall C, Wolfe CDA. 2007. Costs of stroke borne by individuals and families: user-led development of a patient based cost measure. *Cerebrovascular Diseases,* 23(S2) 17

Fudge N, Wolfe CDA, McKevitt C. 2006. An ethnographic approach to evaluation of user involvement in stroke service development. *Journal of Epidemiology & Community Health*, 60(S1) A4-5

Fudge N, Wolfe CDA, McKevitt C. 2006. Can people with stroke be involved in developing stroke services? *Cerebrovascular Diseases*, 21(S4) 5.

Fudge N, Wolfe CDA, McKevitt C. 2005. User involvement in stroke research: rationale, examples and prospects. *Cerebrovascular Diseases*, 19(S2) 129.

doi: 10.1111/j.1369-7625.2009.00573.x

What is involvement in research and what does it achieve? Reflections on a pilot study of the personal costs of stroke

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Keywords: ethnography, research, stroke, user involvement

Abstract

Background Health researchers are encouraged to involve service users as partners in their research. There is a need to increase the evidence base of involvement, including an accumulation of empirical accounts of involvement practices, demonstrating how involvement influences research and refinement of the concept itself.

Aims To report the development of a pilot study by academic researchers and stroke service users belonging to a user research group to investigate costs of stroke to individuals and families; to reflect on what this example of user involvement achieved and implications for what involvement means.

Methods We conducted a 2-year ethnographic study that included participant observation, formal and informal interviews with professionals and user group members and documentary analysis. Data were systematically recorded to permit description of processes and reflexive analysis.

Results and conclusions We report on five stages of the research process from service user identification of a research question to interpretation of pilot study findings. Professional researchers led the research process and developed a novel method to involve stroke service users in the development of a questionnaire. Some academic colleagues questioned the value of the proposed investigation as it did not appear to conform to implicit criteria of quality research. We argue that the moral status that user involvement has acquired means that academics' concerns about quality did not prevent the pilot study from being conducted. We suggest that much of what was undertaken might be considered standard good practice in developing new research studies but also identify additional benefits of user involvement. Implications for conceptual development and evaluation are discussed.

Introduction

Over the past decade professional health researchers in the United Kingdom have been encouraged to involve the public and users of services at all stages of the research process including development of proposals, conduct of studies and dissemination of findings.[1,2] Involvement in research is currently broadly defined but the dominant definition – for example, offered in guidance to researchers applying to major UK funding bodies – is that promoted by INVOLVE,[3] which implicitly draws on Arnstein's well-known hierarchy of involvement.[4] Involvement can take the form of consultation of lay people by professionals; collaboration between professionals and service users, or it can take the form of 'user-led' research. A fundamental principle is that research that involves users transforms them from research subjects into partners or researchers.[3]

User involvement in research is promoted for different reasons. For example, it is argued that user involvement improves research quality by producing research that is more relevant, more likely to be put into practice and lead to improvements in population health.[3] Another argument relates to the desire to democratize this sphere of civic life. Taking its cue from the more or less overtly political arguments articulated by those active in embodied health movements[5] (such as groups of mental health service users) this rationale seeks the empowerment of oppressed individuals and groups, through knowledge exchange and the facilitation of their active participation in the identification of research needs and in the research process.[6]

The aims of user involvement and its potential impact are far reaching. However, as has been previously argued, there is not substantial evidence of claims made on its behalf.[7,8] If the policy rhetoric that has so far driven the user involvement project is to be substantiated, further evidence of its effects is required. Boote *et al.*[7] called for more research to assess the effectiveness of 'consumer involvement' in research, identifying four key areas requiring investigation. These were clarification of the concept of involvement in health research; generation of evidence of how involvement influences research drawing on a variety of research settings and topics; development of methods to measure and evaluate the influence of involvement on research; and identification of factors leading to successful involvement, starting with consensus of what this might look like, from the perspectives of both service users and researchers.

A number of studies are responding to the call to assess the practices and impact of user involvement in research and the concept itself is being elaborated both through debate and the development of more sophisticated typologies of involvement.[9] Factors promoting the involvement of users in research have been reported to include 'good working relationships' between professional researchers and service users enabled by mutual respect and an effort on the part of researchers to promote equality in the face of a relationship characterized by an imbalance of power.[10] A structured approach has been advocated, with appropriate training of service users to enable them to understand and take part in research development and conduct.[11] Paying citizens who are involved in research is a contested issue but some have identified this as an enabler of user involvement.[12] Reported barriers to user involvement include inadequate resources (such as time and money) and the gulf between researcher and layperson created by expert language and paradigms.[10] Studies have also reported that user involvement promotes research quality as it allows research questions to arise out of service user experience (research questions are more relevant) and it provides the opportunity to devise methods that will enhance researchers' ability to collect data.[13] Reported consequences of user involvement studies include 'empowerment' of users, given new opportunities for personal development and new roles for researchers as facilitator, guide, donor of expertise.[10–13] User involvement has also been described as leading to new problems creating scientific and ethical dilemmas that so far remain unresolved.[14]

In this paper we report an experience of user involvement in the development and conduct of a pilot study to investigate costs of illness borne by stroke survivors and their families. We present our data as an empirical example of user involvement practice in a particular research setting and focused on a specific research question. We further aim to use the data to consider two of the key areas requiring research identified by Boote *et al.*[7]: consideration of how and why involvement influences research and implications for development of the concept of involvement in research.

Context

Relatively little has been reported in the literature about involving stroke service users in research, although there are published reports of involving stroke service users in the development of methods for recruitment to clinical trials[14,15] and in the development of a survey of public stroke awareness.[16] Stroke is a major cause of mortality and adult disability. It is estimated that there are 110 000 new cases annually in England[17] with about 300 000 people living with moderate to severe stroke related disabilities.[18] Stroke frequently causes patients to have an increased dependence on others resulting in longer hospital stays, admission to a nursing home and the need for assistance from other people once back home.[17]

Most research looking at the cost of stroke focuses on the cost to government and the health services. For example, the recent report on stroke care in the United Kingdom by the National Audit Office estimated 'the burden of stroke' including total direct health care costs for the period 2003–04 at £2.8 billion. This included hospital stays, investigations, medications and so on. It also estimated that families pay nursing home costs of £2.4 billion per year. Indirect costs – that is lost income due to death and disability, as well as benefit payments – amount to £1.8 billion per year.[17] However, little is known about additional costs paid by the individual who has a stroke and/or by their family, nor how people deal with such costs or loss of income.

The need for a study investigating the costs of stroke was identified by the Stroke Research Patients and Family Group (SRPFG). This group is a standing forum of stroke survivors/family members and researchers associated with the King's College London Stroke Research Programme. Research undertaken within the programme includes the on-going population-based South London Stroke Register (SLSR), a vehicle for epidemiological and health services research. The SRPFG was established by professional researchers (CM, NF, CW) in 2006 to promote the involvement of people with stroke and family members in the stroke research programme, not merely as research subjects. Activities include 6-weekly meetings to discuss research findings, plan new studies and produce a biannual research newsletter disseminating findings to SLSR participants. The process of establishing the SRPFG was evaluated through an ethnographic study undertaken by professional researchers CM and NF.

The topic of costs of stroke was identified by group members during a discussion that took place in a regular group meeting. Thus SRPFG members had identified a gap in knowledge arising from their own experiences in the aftermath of stroke that we – group members and professional researchers – sought to investigate. Group members expressed the hope that by identifying the economic burden imposed by stroke they might use the information to highlight their situation and use this in future campaigning directed at local and national government.

Methods

Data for this descriptive account of processes and our reflections on these were recorded during the ethnographic study[19] investigating stroke service user involvement in service development and research in an inner city area of London.[20] The study was approved by the St Thomas' Hospital Local Research Ethics Committee. The ethnography was conducted by CM and NF and entailed participant observation, formal qualitative interviews with stroke service users and professionals and documentary analysis. Participant observation data were recorded using detailed field notes and a reflexive diary. Formal interviews were conducted with participants including members of the SRPFG and academic researchers and digitally recorded and transcribed for analysis. QSR Nvivo 2.0 (QSR, Doncaster, Australia) was used for data storage and management. NF was primarily responsible for recording ethnographic data and as participant observer aided CM in establishing user involvement: recruiting stroke survivors to the SRPFG; setting meeting agendas; chairing meetings; performing administrative tasks; encouraging stroke researchers to participate in meetings. CM and NF conducted thematic analysis of field notes, the reflexive diary, interview transcripts and documents. Analysis was undertaken concurrently with data collection and iteratively directed data collection. Strategies to enhance the validity of our data and interpretation included: having more than one researcher involved in analysis, sharing drafts of the paper with informants for comment and validation, incorporation of reflexive procedures from the outset of the study, attention to the variety of perceptions and experiences of study participants.[21]

Results

The research process

Stage 1: identifying the method

The first task was to identify an appropriate research method. The professional researchers discussed possible methods with a health economist who felt that the topic was of little interest since societal costs of stroke had already been estimated and published. The professional researchers argued that this did not include 'out of pocket' costs but discussions went no further. We carried out a literature search to identify methods previously used to measure out of pocket costs to patients. These included various diary methods; an economic study of stroke costs which included 'out of pocket' costs[22]; and a survey questionnaire to investigate generic patient costs that had been developed but not used.[23] This questionnaire was also rather long running to more than 70 pages of annotated questions.

In the next regular meeting of the SRPFG, professional researchers reported what they had found and led discussions about appropriate methods, raising possible advantages and disadvantages of available methods. SRPFG members argued that a diary method was not practical since patients and carers were unlikely to complete a diary in the early weeks and months after stroke when they may also be going through major life changes. The professional researchers proposed using the generic questionnaire to develop a novel stroke specific questionnaire, which could be tested in a small sample of stroke survivors. SRPFG members were enthusiastic about the proposal.

Stage 2: developing the questionnaire

Questionnaire development began with open-ended interviews with people with stroke and family members to understand the experiences of individuals and families. These interviews were of two types: researcher interviews and guided conversations. Researchers conducted two preliminary interviews (with two couples) to get a broad idea about what topics were important. Data were analysed to identify topics to include in a topic guide for guided conversations. Adopting similar principles to that of the peer ethnographic approach[25] CM developed the guided conversation method to allow SRPFG members to interview each other, as a way of systematically reproducing conversations and exchange of information that take place naturally between group members during meetings. Nine people from the SRPFG took part in guided conversations during a specially conducted meeting. Participants were assembled into three conversation groupings and used the topic guide as a script or prompt to interview each other about their experiences of costs post stroke. Participants reported feeling at greater ease being interviewed by someone who had been in a similar situation as themselves. Two other group members unable to take part in the guided conversations meeting were interviewed by a professional researcher. Interviews and guided conversations were tape-recorded, and data analysed by professional researchers to finalize topics for inclusion in the costs of stroke questionnaire.

Questionnaire design was led by a medical student with an interest in the cost of stroke (and who subsequently used this material for a student project) assisted by stroke research programme colleagues with expertise in questionnaire design. This drew on interview data and the generic patient costs questionnaire. Members of the SRPFG and researchers read the draft questionnaire to check for comprehensiveness (that all topics had been included) and for clarity. Some changes were made to the wording of the questionnaire to reduce ambiguity.

The questionnaire covered several areas of cost including: payment for adaptations to the home, medications, alternative therapies, changes in diet (e.g. buying diabetic/organic food), nutritional supplements, clothing suitable for disability, transport and direct and indirect loss of family income.

Stage 3: conducting the survey

The questionnaire was administered to consenting participants of the SLSR during the scheduled three or six month follow-up. This is a face to face interview in which fieldworkers collect a large amount of clinical, social and service use data for the purposes of the population register. Participants included SLSR recruits living at home or in sheltered accommodation but excluded those still in hospital after stroke; living in institutionalized care (e.g. nursing home, residential home, long-term care, community or private hospitals). Where the person with stroke could not be interviewed (e.g. due to communication or cognitive impairment), the next-of-kin or a carer was interviewed. The survey was conducted over six months.

Stage 4: the survey analysis and findings

Response frequencies were tabulated by the medical student, with additional socio-demographic data and disability level (Barthel Index) drawn from data routinely collected for the SLSR.

Fifty-five people agreed to take part in the study but one did not provide any information about costs of stroke. Responders were aged 18–86 years (average 69) and 61% were male; 65% were from white ethnic groups, 23% from black ethnic groups, 10% from other ethnic groups; (2% missing). Using the Barthel Index, a measure of activities of daily living widely used in stroke research, 43% were classified as independent; 32% mildly disabled and 24% moderately to severely disabled; (1% missing). Key findings from the pilot study are outlined in Box 1.

Stage 5: interpreting the results

The results were presented to the SRPFG in a regular meeting, with professional researchers leading discussion on how they might be interpreted. Researchers reminded group members that this was a pilot study that aimed to test the feasibility of the method, and that a larger study would be required for a more reliable picture of the out-of-pocket costs of stroke. Nevertheless the analysis had shown that most survey participants reported at least one out-of-pocket expense. The survey also identified a small group of people who paid for adaptations to the home

Box 1 Expenses reported by responders

6/25 responders needing adaptations to their homes as a result of stroke paid for these spending. Individual expenditure varied widely but in total all six spent £14 660

2/4 people needing specially adapted equipment paid for this themselves, spending a total of £72

Nine people reported having to buy new clothing, mainly shoes with Velcro fastenings, spending a total of £1570

7/13 people needing help with personal care paid for this themselves spending £25.03 per week on average (range £5.00–58.24)

4/24 people needing help with housework paid for this, with weekly costs ranging from £10–100

1/4 people responsible for child care at the time of stroke, reported having to pay for this after stroke, amounting to £50 per week

Five people were not exempt from prescription charges, each spending £30–50 per month. Five people bought supplements since their stroke, each spending on average £32.36 per month

11/26 people making changes to their diet since their stroke now spent more per week on food

Four people paid for treatments (including physiotherapy, acupuncture, Reiki) spending altogether £8505

Eight people reported a decrease in their income after their stroke because they could no longer work, with loss of income ranging from £550–2500 per month and for private therapy, raising questions that need to be explored in more detail about these costs. Researchers also reported feedback from the fieldworkers carrying out the survey, including their views that participants felt that this was a meaningful research question and were happy to take part. However, relatively few individuals were able to report specific costs incurred, either because they had not kept track of additional expenses, or now left their financial affairs to their adult children. Group members suggested that it would be worth pursuing a larger scale study but also looking in more depth at some topics, such as why some people paid for private therapies, whether orthodox or alternative.

Reflections on the process

Having described the development of the method to assess costs of stroke to individuals and families, we now reflect on two aspects of this process: the particularities of involving stroke survivors and family members, and the position of user involvement research vis-a-vis 'traditional' academic research.

Involving stroke service users in research

High proportions of stroke survivors have ongoing disabilities, including problems with mobility, speech and cognition.[25] Members of the SRPFG include wheelchair users, people with reduced mobility and communication difficulties. These present logistic problems which require forward planning and involvement activities perhaps require greater time than might otherwise be needed. As a category of service user, stroke survivors differ from other groups where the desire to influence service development and research may be linked to consciousness as an oppressed group and a commitment to social change. Although members of the SRPFG are concerned to see improvements in stroke care, UK stroke survivors do not appear to be politicized, nor do they have a history of activism, collective sense of oppression, or organisation as an embodied health movement, prepared to challenge experts seen as paternalistic or excluding them from decision making processes. To a large extent this shaped the model of involvement that so far we have put into practice, meaning that the professional researchers, although acting on the SRPFG's desire to investigate the topic of costs of stroke, nevertheless led the development of the pilot study. This entailed using professional researcher skills to conduct literature searches, conduct initial interviews, develop the guided conversation method, conduct and analyse data and prepare results for consideration and interpretation by SRPFG members. Far from being a conscious decision to retain power, this was a pragmatic decision, with researchers proposing procedures and SRPFG members agreeing. It is likely that their agreement was dependent on their level of knowledge and skill, and their readiness to see the professional researchers as the technical experts. It is also possible that this relationship may change as group members learn more about research and become more willing to critique the way that research is conducted.

Situating user research in the academe

Reporting the intention to pursue this user generated study to academic colleagues, the professional researchers were met with different reactions. While some stroke researcher colleagues found the question interesting, others expressed scepticism, suggesting that scientific research could not emanate from 'subjects' because of their inevitable bias. More importantly there were concerns about how this piece of work might be reconciled to the need to demonstrate academic authenticity. In other words, questions were asked about why the pilot study was not 'properly' funded, whether ethics approval needed to be sought over and above that already obtained for the larger ethnographic study, and what types of publication the exercise might result in. At the same time the professional researchers felt obliged to address possible concerns that SRPFG members might have about the length of time required to conduct the pilot study, especially given their view that the results might be useful in political campaigning. Thus the professional researchers acted as brokers and translators, defending what appeared to be unorthodox to academic colleagues and explaining the realities of academic research to SRPFG members.

Discussion

We have described the process of developing a pilot study of the costs of stroke borne by individuals and families, which took place in the context of an on-going forum established to promote service user involvement in stroke research. A research topic that emanated from stroke service user experience and concerns was identified and a feasible method was developed. This included developing the guided conversation method that permitted service users to conduct qualitative interviews with their peers. The pilot identified practical problems that would need to be acknowledged in this study, including the problem of recall. Thus it was certainly feasible for users to be involved in research, identifying a topic and participating in the development of a novel research tool. However, it could be argued that development and piloting of a novel research instrument might have followed similar steps even without the self-conscious user involvement approach we took. Searching the literature, contacting researchers with relevant experience in the field, qualitative interviewing of potential responders for item generation, field testing the questionnaire and review are all standard elements of good practice in questionnaire development. In fact, the topic of costs of illness and costs of stroke had already been identified by another stroke research group[23] without evidence of these being instigated by patient or lay groups.

This raises the question of what additional benefit was provided by commitment to involve service users. We suggest that there are two main benefits. First, the fact that users themselves identified the topic meant that it was pursued at all. In the face of the lukewarm reaction of academic colleagues, we were assisted by the fact that involving users in research is a governance requirement. This in effect sanctioned the work. We were also assisted, we believe, by the moral status that user involvement has come to acquire.[26] In the absence of unequivocal evidence of benefit, the moral power of 'users' as a category and the need to carry out user involvement activities meant that while the pilot might be critiqued on academic terms, it was not going to be thwarted. While much of the published literature assumes that researchers have power and service users need to be empowered, we suggest that it may be illuminating to investigate further the moral status of service users as a category and the kind of power this might have in driving the user involvement project.

Secondly, the question raised by the SRPFG in effect reconfigured the topic of costs of stroke as it is usually construed by academic researchers and policy makers. Epidemiology and health economics construct the problem as the *burden* of stroke, focusing on costs to society. Investigating the expenses borne by individuals and families corrects this to a certain extent showing that the costs are not only borne by society but also by individuals and family members.

Therefore, in terms of *how and why* involvement influences health research, our experience suggests that this might occur in three ways: it can lead to the identification of questions regarded as important and relevant to service users (although this perception may not be shared by professionals); it can help refine methodology; and it might help reconceptualize problems in ways that incorporate the experience of service users.

The need to develop a more sophisticated conceptual model of user involvement in research has been identified.[7,27] Drawing on the literature from a wide range of areas, Oliver *et al.*[9] have proposed a more complex conceptual framework of public involvement in research based on type of involvement (individuals or members of organized groups), origin of involvement (invitation from professionals or in response to citizen action) and level of involvement defined as consultation, collaboration user-led. This model represents a development in ways of thinking about user involvement but does not necessarily overcome the problem of thinking about involvement as static rather than dynamic. The type of involvement we achieved might be categorized as both user-led and collaborative, with the contributions and roles of professional researchers and SRPFG members shifting throughout the process according to the tasks at hand and the available level of skills. As an idea it was user led and user driven as the impetus to do the work came from SRPFG members. In conducting the study it was mostly researcher led with collaboration between researchers and users.

However, our experience suggests that conceptual development of user involvement in research needs to move beyond development of typologies based on processes and to consider user involvement phenomenologically. What kind of phenomenon is this; or rather what kinds of user involvement are being constructed as researchers and lay people put involvement into practice? Among the actors engaged in our story of user involvement, there was a wide range of motivations, views and objectives, suggesting that attention to user involvement as a social phenomenon will require investigation of the goals and actions of individuals (professional and non) and groups who instigate and engage in involvement practices. Rather than involving users as individuals, members of community groups or in response to citizen action, our approach aimed to set up the means to promote on-going dialogue between academic researchers and people affected by stroke. This means that activities, relationships and expectations of both parties may change over time, as may our understanding of what user involvement is or should be.

Conclusions

The concern to avoid tokenistic user involvement[8] implies a need to identify and promote 'meaningful' user involvement. This requires an agreed definition of what might constitute success, itself dependent on the definition of user involvement adopted. Different aspects of user involvement imply different criteria. For example, aspects of success relating to research quality require attention to relevant components such as whether the boundaries of knowledge are being pushed, new questions, new methods and new solutions being identified and put into practice. Evaluating the success of user involvement in empowering service users and democratizing science will require attention to knowledge exchange and changes in knowledge and expectations of both service users and researchers.

Costs of Stroke Study Team

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*Sadly, John Matthews and Patrick Rosheuvel died before this paper was finalized.

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RESEARCH

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

Increasing rates of chronic disease, the need to contain costs, and raised patient expectations lie behind efforts to reform healthcare services.[1] Reforms to the United Kingdom's National Health Service include efforts to transform the relationship between patients and professionals. Patients are being encouraged to exercise greater control over their own health care and to become more involved in the development of health services.[2-4] 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.[5] Policy documents are, however, less clear about how involvement should be undertaken. They cite a raft of arrangements that fall under the umbrella of involvement: patient choice, patient surveys, Patient Advice and Liaison Services, patient forums, and networks, Overview and Scrutiny Committees, complaints procedures, NHS foundation trust boards, and the duty to consult and involve patients and the public in the planning and development of health services.[6] Evidence of the relationship between user involvement and improved outcomes is, however, weak.[7-9] Several authors have commented on the lack of a precise definition of user involvement and that the aims of user involvement are multiple and go beyond improving health care.[10 11] In policy documents user involvement is presented as a quality issue, attributed with the capability to make improvements to services. However other analysts have explained the phenomenon of user involvement from several philosophical and political perspectives: consumerism, democracy and citizenship, and the rise of patient pressure groups.[12]

These factors highlight the need for increased understanding about how the policy of user involvement is interpreted in health service organisations and how these interpretations shape how user involvement is put into practice. To elucidate these questions we carried out an ethnographic study[13] of an initiative to involve people with stroke and their relatives (service users) in the modernisation of stroke services.

METHODS

Stroke services, from acute to long term care, have been recognised as failing to meet the needs of patients and their families.[14] In 2004 a three year programme of service improvement was initiated to modernise stroke services in two London boroughs, with charitable funding. The programme was delivered by NHS employees and clinicians and aimed to reduce the number of first time strokes and to modernise acute and community stroke services. The two inner city boroughs where the fieldwork took place have ethnically diverse populations. Levels of deprivation and deaths from stroke are higher than the national average.[15 16]

Data collection

Since our study was based within a programme of stroke research at King's College London, whose earlier findings had been key to establishing the need for the programme, access to the programme was easily negotiated. Fieldwork began in December 2004, at the beginning of the programme before service users were recruited, and continued for just over two years. It consisted of participant observation, collection of documentary evidence, and semistructured interviews (box 1) to record how user involvement was implemented and maintained, data on participants, activities, and outputs. Participant observation entailed working with programme staff, participating at recruitment events, and programme meetings. The researcher (NF) made detailed ethnographic notes and kept a reflexive diary.[17]

We carried out semistructured interviews with service users and programme staff who had worked closely with service users (box 1). Interviews investigated professional and service user interpretations of involvement, barriers and facilitators to its implementation, and impact. We purposively selected service user interviewees to include a range of people for sex, age, and stroke severity. Interviews were tape recorded with permission and transcribed in full for analysis. When interviewees refused to be recorded (n=3) we made detailed notes during the interview, which were written up immediately after the interview.

Box 1: Summary of data collected

Participant observation and discussions with key informants

Four meetings to plan recruitment

Telephone contact and visits, with local voluntary and community organisations to assist with recruitment

Telephone contact with people who had had a stroke to invite them to take part in the programme

Four "join in events" to recruit people with stroke and to encourage family members to get involved

Two events at general practices to raise awareness of stroke and three planning meetings

Five taster sessions to introduce interested service users to specific project areas

Four training sessions for service users who want to be involved

Five programme management meetings

Three meetings of the training group

Twenty meetings of the user involvement subgroup

Four meetings of the information group

Programme conference

Semistructured interviews

Seven interviews with people who declined to take part in the programme

Nine interviews with people taking part in the programme

Three interviews with professionals (two programme staff and one general practitioner) working with service users on the programme

Documentary sources

Programme newsletter

Programme documents

Minutes from meetings (programme management group, user involvement subgroup, information group, training group)

Data analysis

Data were stored and managed using QSR Nvivo 2.0 (QSR International, Melbourne, Australia). We carried out thematic analysis of the notes, reflexive diary, interview transcripts, and programme documents. Analysis was done concurrently with data collection and iteratively directed data collection.[18] Every three months the researcher (NF) wrote a summary of the fieldwork and identified emerging themes, patterns, categories, and anomalies in the data. The notes, diary, and programme documents were reread to code additional patterns and themes. These were discussed and iteratively reviewed with the principal investigator (CM). On a whiteboard we grouped these patterns and themes into larger overarching themes to understand how the interpretation of user involvement and other factors shaped its implementation in the programme. The emerging themes were reported to programme staff and service users to identify additional data that might challenge preliminary analyses.[19]

RESULTS

"People with stroke in the driving seat": the ethos of user involvement in the programme

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" (document 1: programme proposal). 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. It was intended as an infrastructure work stream to support the three other work streams. A manager was employed to lead on 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, with many members citing other work priorities as the reason for their inability to attend. User involvement was well resourced, with funds available to employ a user involvement lead working 50% of her or his time on user involvement activities, administrative support, transport costs for service users to attend meetings, venue hire, and expenses for service users (although take-up of this was minimal).

Recruiting and directing service users

Two one day events were held to publicise the programme to service users and the areas in which they might participate. About 500 invitations were distributed to stroke survivors using a mixture of consecutive and convenience sampling through a community stroke register, voluntary groups, and hospital and community clinicians. Transport was offered and lunch was provided.

In total, 60 service users attended the two initial events. Recruitment was ongoing throughout the two years. Overall, details of 176 service users (158 stroke survivors, 18 carers) were entered on a user

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

involvement database over the two years. Based on estimates of local stroke prevalence[20 21] this represents about 3.3% of stroke survivors in the study area. However, the database includes both those who went on to participate in programme activities, as well as those who attended only one event.

Service users who attended initial recruitment meetings were invited to identify their priorities for stroke service improvement. Programme staff recorded these problems but announced that one area—transport—was beyond the remit of the programme. Staff encouraged attenders to participate in one or more activities from a predefined 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, focusing on skills needed to participate and background to the NHS and the programme. Professionals who were already members of the project management group were also offered training about working with service users. Despite the stated aim to involve service users throughout the programme, in practice this was limited mainly to the infrastructure work stream (figure).

User involvement activities and outputs

The table reports the activities and outputs of user involvement across the programme work streams where service users were involved. Over the two years of our evaluation the programme succeeded in engaging users to produce a range of outputs aimed at improving specific components of stroke care. Intuitively some outputs would seem to have higher quality because of the involvement of users. For example, interviewees asserted that involving service users ensured that the staff training and patient information materials that were developed were more relevant because they reflected the views of people affected by stroke. Furthermore, development of staff training materials used an established method, which the user involvement lead reported had been positively evaluated. Information resources developed through the programme have not been formally evaluated making it difficult to assess whether this led to improved outcomes for patients. A Cochrane review on effects of user involvement found that patient information leaflets developed with service users were more relevant, readable, and understandable to patients than those developed without input from service users, but did not reduce patient worries or anxieties.[9]

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. For example, they reported satisfaction in feeling that professionals were listening to them, that their ideas were acted on, and that their experience of stroke was being harnessed to help others. During fieldwork carried out in group meetings and one-off events 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.

Processes and outputs

Area	Processes	Outputs
Information	Specific group established for service users interested in developing information; additional groups established for specific patient groups such as younger people with stroke who have children; raising awareness events at general practices run by service users and professionals	Identifying information needs and time points when information is required; material developed (patient handbook, picture menus in stroke units, information about parenting after stroke); events allowed service users to share information with other service users
Training healthcare professionals	Specific group established for service users interested in training healthcare professionals; raising awareness events at general practices run by service users and professionals; service users attended training sessions to speak directly to professionals	Good practice guidance and accompanying DVD of patients' experiences produced and used in training sessions; training sessions and events at general practices allowed service users to educate staff on what it is like having a stroke and how they want to be cared for
Support	Training given to service users interested in providing peer support; recruiting service users to lead project to provide long term support	Peer support service established; support delivered by service users; meetings with local council to raise awareness of problems associated with stroke
Programme management group	Service users trained to take part in programme management group	Service users co-opted on to existing group and take part in group accountable for programme; service users on interview panel for new employees
Acute services	Patients asked to complete patient satisfaction surveys and offer suggestions for improvement	Results from survey compiled and reported to steering group
Community services	Service users consulted at "sign off" event for staff competencies	Competency skills for staff working in community services
Prevention	Service users invited to take part in prevention steering group	Service user co-opted on to existing steering group and takes part in group accountable for work stream

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. Factors that might explain this were organisational structure and responsibility for user involvement, communicating involvement, types of knowledge, and patients' and professionals' understanding of involvement.

Organisational structure and responsibility for user involvement

Although all work streams were required to involve service users, in practice 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 dedicated person responsible for user involvement but that 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. Given the structure of the programme it is perhaps not surprising that 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 patient satisfaction surveys and suggestion boxes or consultation with service users in the later stages of a project.

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 project management roles. Of five service users who underwent training to participate in the programme management group only two members retained their membership throughout the fieldwork period. No service users were interested in joining the user involvement subgroup—a group to manage the involvement of service users in the programme. By comparison the training, information, and peer support related projects had up to 15 members regularly attending meetings. When recruiting to these projects, staff could point to tangible outputs or products, such as developing information leaflets or good practice guidance to inform staff training, unlike other projects with less tangible outputs such as reorganising community clinical services, or project management. Service users also compared participating in time limited projects with a defined output with the longer term commitment required of management roles.

Box 2: Transformation from patients to service users

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*)

Sarah, one of the professionals on the programme, suggested that we move on to the next item and asked her colleague Simon if he wanted to introduce the questionnaire. Simon told the group about TIAs (transient ischaemic attacks) or mini strokes and explained that part of the work of the programme is to get more people going to TIA clinics and then to assess how the clinic is being run from the perspective of clinic users. Simon handed out a questionnaire and explained to the group how he had designed this questionnaire and that he had "brought it to you guys" to see if it was understandable and the right way to "check patient feedback." There was a bit of confusion from the service users—some people started to fill in the questionnaire while others said they did not see how the questionnaire was relevant to them since they had not had a TIA or been to this clinic before. Nora said that her husband had had a mini stroke and she would take the questionnaire home and ask him to fill it in. Simon said that it was OK, she did not need to do that. (*Field notes from a meeting of the information group, 29 November 2005*)

Types of knowledge

Projects that service users were involved in required them to draw on their own 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. For example, when the user involvement lead asked colleagues why service users had not been involved in a project to map usage of community services, they suggested that the work would have been too difficult for service users to undertake.

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 to service planning and development, a transformation that was not always easily achieved (box 2).

Patient and professional understandings of involvement

The range of interpretations that service users and professionals had of "user involvement" and what it should entail may have further influenced the forms that this took in the programme.

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, tending to involve service users at the end of the process to get approval for a product or service. Both these interpretations were able to coexist without raising problems.

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 (box 3).

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 also found, professionals control the interpretation of involvement and the ways that service users are involved.[22-25] This may have implications for the ability of user involvement to bring about fundamental change.

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 or not. Previous studies have looked at responses of different professional categories to the idea of user involvement suggesting responses ascribe to the interests of the particular discipline.[26 27] Here we observed differences within professional and service user groupings based on individual ideologies, circumstances, and needs. Within professional groupings we identified two categories. Firstly, professionals who viewed user involvement as an exercise in democracy and promoted patients' expertise as valid as that of professionals were identified. In contrast there were 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, however, 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[28 29] and the long history of poor quality stroke services in the UK,[14 30] user involvement in the specialty of stroke is only now beginning to emerge. Patients with stroke have not organised themselves into activist grass roots movements, as has occurred in health areas such as HIV/AIDS, maternity services, breast cancer, and mental health.[25 31-33] Among the stroke population is a high proportion of older adults, people with disabilities, and those who are socially isolated.[28] This raises questions about whether characteristics of certain patient groups make user involvement more or less difficult to implement.

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. This 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?

The debate on representativeness of service users is long standing.[34] Promoters of involvement have insisted that we focus on inclusion and diversity of service users rather than representativeness.[35] 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 to those involved over those who are not. 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.[10]

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. Our ethnography provides only part of the story of a project within which the involvement of service users continues to develop. A stroke service user network is being established to continue three projects: peer support, training healthcare professionals, and developing information resources. This further emphasises

Box 3: Service users' interpretation and understanding of user involvement

A right for patients to have a say about the services they use

Service user 4: It's nothing new—this has been going on for centuries you know so why would we think it is something new? Women had to fight for their rights, tie themselves to railings things like that to vote so why would we think it is something new? You have to campaign for anything you want—it's never given to you. (*Interview, 19 January 2006*)

Carer at the introductory event: If you let the NHS decide you won't get the right answers. If you speak to users you will get the answers. Doctors must form services based on what people need. (*Field notes from an event, 21 March 2005*)

Opportunity to meet others in a similar situation

Service user 5: Well as I said before, it [participating in the programme] made me go to my doctor and find out as to, you know, what happened to me when I had a stroke which I probably wouldn't have bothered to do. Apart from the fact of hearing of other people's experiences of stroke cos I mean the people there the experiences are so different. You know there's Vera who had lots of small ones before the main one and others that have had a small one and then the big one . . . so that was a positive thing for me to sort of go and find out . . . yeah and you know meeting people and finding out their different experiences. It's nice to meet new people isn't it? (*Interview, 25 January 2006*)

Finding out about the latest developments in stroke medicine

Interviewer: Why did you want to go to the event?

Service user 6: I wanted to see if there was any progress made like you know.

Interviewer: What kind of progress?

Service user 6: Discovered any new medical things like you know. Cos I mean you read in the papers, especially in *The Mail* today it's all medical you know and there's things in there I mean there's a man who's just had all his stomach took away and things like that and you just don't realise such things can happen—I know they do some wonderful things you know. But I went to see if there's any, as I say, new effects come on the market. (*Interview, 9 August 2005*)

Accessing health or social care services

Mrs James attended a number of the one-off events, but didn't want to take part in any of the smaller projects. Her main concern at the events was her housing situation: she and her husband, who was in a wheelchair as a result of his stroke, were housed in the top floor of a high rise block of flats with lifts that worked intermittently, making it impossible for them to leave the flat in case the lifts were broken and they couldn't get back up to their flat. Mrs James told her story to some senior social care managers who were also present at the event. One in particular told her who she needed to phone to get things sorted out and then gave her his card and told her to contact him directly if she still didn't have any luck with getting things sorted out. (*Field notes from an event, 11 October 2005*)

A service to aid recovery from stroke

I asked Grace how she heard about the Join In Event. She said that she heard about it at the day centre: a lady was there who was talking about it and then they sent her a letter asking her if she wanted to go to the event. I asked Grace why she decided to go to the event. She said that she just wants "to know what's happened, what's going on." I asked her what she thought of the event. She said that it was "quite alright" but that she didn't think she could improve any more than she already had: five years after her stroke and she still couldn't move her hand properly. I asked her what she thought the purpose of the event was. Grace said that maybe it was for other people who had "just had a stroke maybe two or three months ago," but when you have had a stroke quite a long time ago there isn't really anything that they can do to improve things for you. (*Field notes from telephone interview, 5 September 2005*)

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*)

the time required to fully develop and embed user involvement within an organisation. Thirdly, the ethnographic approach we have taken is an interpretive one and does not provide the only or most legitimate account, but an account that is open to discussion and critique.[13]

Other studies looking at user involvement in practice have tended to use qualitative methods such as interviews and non-participant observation.[22 23] 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.[36] We shared our findings with study participants to challenge our preliminary analysis.[19] There were some minor factual corrections but no disagreement with the analysis we presented.

Implications for policy and practice

Our findings have implications for those concerned with developing the evidence base for the effects of user involvement. There have been calls for use of randomised controlled trials to provide evidence of impact.[9] Through our ethnography we have provided evidence of the multiple meanings assigned to user involvement and multiple outputs of involvement, a theme discussed in published opinion pieces[11] and reported in research.[10] This suggests that identifying the active component and anticipated outcomes of user involvement necessary for undertaking a randomised controlled trial to provide evidence may be difficult. Other evaluation methods may be more appropriate for evaluating user involvement as a complex intervention, taking into account factors that may shape and constrain user involvement in health care.

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 (HIV/AIDS, mental health, and breast cancer), user involvement in this study was professionally led. Had a stroke activist group existed, involvement in this study may have looked different from that observed. What we have observed is the start of something that might develop in a different direction as the roles of patients with stroke transform. 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. Greater debate is required among those implementing the policy as to why user involvement is desired, what is hoped to be achieved by increasing involvement of service users in the health service, as well as more evidence and critical analysis of the improvements user involvement is said to bring.

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

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REVIEW

Involving older people in health research

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Abstract

Background it is a UK policy requirement to involve patients and the public in health research as active partners.
Objective we reviewed published reports of studies which involved older people in commissioning, prioritising, designing, conducting or disseminating research.
Search strategy and selection criteria systematic searches of databases (PubMed, SCI-EXPANDED, SSCI, A&HCI, ASSIA, Embase, CINAHL and Medline) for English language studies published between 1995 and 2005 which had involved older people as partners in the research process as opposed to research subjects. Articles were reviewed by two authors using a standardised matrix for data extraction.
Results thirty studies were included and classified according to the stage in the research process in which older people were involved. Barriers to involving older people were: cultural divisions, language barriers, research skills capacity, ill health, time and resources. Four of the studies had been formally evaluated to identify the impact of involvement. Evaluation focussed on the impact on participants rather than on impact on research processes and outcomes. Benefits to participants included: increased knowledge, awareness and confidence, meeting others in similar situations, empowering older people to become active in their community regarding decisions/policies which affect them.
Conclusions factors hindering the involvement of older people in research were the same as reported factors hindering involvement of younger people, suggesting that age, per se, is not a barrier. To demonstrate the impact of user involvement on research quality, the definition of user involvement requires clarification, and systematic evaluation of research involving older people needs to be developed.

Keywords: *user involvement, consumer participation, research, elderly, older people, systematic review*

Introduction

The involvement of patients and the public in research has had a long history in fields such as disability, mental health, HIV/AIDS, breast cancer and environmental health [1]. Dissatisfaction with the way research represents patient groups or with the lack of research into areas deemed important, has driven activists to demand a role and a say in how research is conducted [1]. Over the past decade, UK government policy has formalised and promoted this activity under the umbrella term 'user involvement' [2]. The involvement of patients, carers and the public is at the heart of the National Health Service [**3, 4**] and it is a policy requirement for researchers to consult and involve service users in research [**5**].

Involve the Department of Health funded body to promote the involvement of patients and the public in health and social care research, define user involvement as 'an active partnership between the public and researchers in the research process, rather than the use of people as the "subjects" of research' [**6**]. Policy documents suggest that involvement leads to research of greater relevance to people, findings which are more likely to be implemented [**5, 6**] and empowerment of patients and the public [**4**]. However, a number of reviews have argued that there is little evidence of the impact of involvement on research processes and outcomes [**7, 8**].

Some authors have argued that older people are less consumer oriented than younger people, lack the skills to participate or do not necessarily want to be actively involved in research and developing services [**9**]. Others have commented on the low priority afforded to involving older people in the planning and development of health services [**10**] and the under-representation of older people as subjects of research in research studies and trials [**11**, 12]. The purpose of this review is to establish the scope and extent of the involvement of older people in health research over the past 10 years, to identify reported barriers to the involvement of older people in research and to determine the impact of the involvement of older people on research and on participants.

Methods

We searched English language articles published between 1995 and 2005 using the following databases: PubMed, SCI-EXPANDED, SSCI, A&HCI, Applied Social Sciences Index and Abstracts, Embase, CINAHL and Medline. The search strategy used MeSH and free text terminology combining terms for user involvement (involvement, participation, collaboration, consultation, consumer, user, patient, stakeholder, public, lay) with terms describing research (research, public health, medical research, research agenda, research priorities, research programs, research questions, research methods, participatory research, action research, advisory groups) and older people (older people, geriatric, elderly people). We also searched the bibliographic references of the full-text articles included in the review for further relevant material.

Articles were included if they reported involving older people at any stage of the research process (from commissioning or prioritising research through to the design, conduct and dissemination of research) other than as research subjects. 'Older people' were defined as those over 65 years of age, unless authors defined older people according to different age bands. Where authors did not specify an age, author-defined terms such as 'older people' were used.

We did not use a quality checklist to determine which papers should be included in the review. While this is the usual method for systematic reviews, the approach was not applicable in our case because there is no agreed definition of quality in research projects involving participants. We used Involve's definition of user involvement to determine studies which had actively involved participants: 'doing research "with" or "by" the public, rather than "to", "about" or "for" the public' [6]. In addition, our search was limited to the peer-reviewed literature as this is an accepted indication of quality.

We excluded from the review: exclusively theoretical articles and literature reviews although these were used to inform the analysis and discussion; studies describing the involvement of older people in health promotion activities/interventions, personal/individualised care plans and development of health services; studies that did not specify the ages of people involved; or studies which did not specifically involve older people.

A structured assessment of each article was undertaken to identify: age of users, types of users, degree of involvement in different stages of the research process, roles and tasks undertaken by the older people, barriers to and facilitators of involvement of older people, evidence of evaluation and impact.

Results

Of 2,492 citations initially identified, 35 articles (reporting 30 studies) met the inclusion criteria (see Figure 1) [13–47].

Eleven of the 30 studies originated from the United Kingdom [18, **19, 24, 25, 27, 30, 33, 34, 36, 40, 45, 46**], nine from the USA [13, **16, 17**, 26, **29, 35**, 38, **39, 41**, 42], seven from Canada [14, **15, 20**–22, **31**, 32, 37, 43, 47], one from Australia [23], one from Ireland [**28**] and one from the Netherlands [44].

Of the 30 studies, 10 involved older people in researching health services, looking at aspects such as: equity of, use of and access to services [**16, 17**, 37, **45, 46**]; service evaluation [**41**, 44, 47]; and research to improve and develop services [**33**]. Eleven studies involved older people in research focussing on specific health areas: chronic conditions [**31**]; falls [**15, 36**]; healthy eating [**39**]; mental health [26]; stroke [**27**]; cancer [43]; diabetes [38]; and older people's health in general [13, 18, **19, 29**]. Three studies were concerned with research on health needs assessments [**20**–22, **24, 25**], three with quality of life [14, 23, **34**] and three with assistive technologies [**28, 30, 40**].

We present the data in three sections: the stage of the research process within which older people were involved; factors which facilitate or act as barriers to involving older people; and the impact of involving older people in research. Given that user involvement is promoted through the UK Department of Health policy, Table 1 focuses on the UK literature, describing in greater detail how older people have been involved and the impact of their involvement.

Involvement of older people in the research process

Training

Two studies report older people involved in research training programmes to enable them to participate in research activities [13, 18, **19**, 42]. As part of the training, older people took part in research projects which involved them in interviewing their peers.

Design

Nine studies report the involvement of older people in the preliminary stages of a research study [23, **27, 29, 30**, 37, 38, **40, 41**, 44]. Examples of older people involved in the design of research studies are: understanding concepts such as 'quality of life' and 'quality of care' from the perspective of the older person to develop appropriate research tools [23, 44]; determining the acceptability of a randomised control

Table 1. UK literature

Study	Research question/objective	Participants	Tasks of participants	Reported evaluation and impact
Dewar 2003, 2005 [18, **19**]	Research training courses for older people	Thirty participants aged 50+	• Taking part in training courses	Evaluation by informal discussion and questionnaire. Participants reported: increased confidence; listening skills; awareness of social and political issues; ability to 'confront situations' Training encouraged participants to undertake other activities including: working with policy makers and researchers to prioritise mental health research agenda; interview older people; develop research proposals
Horne 2003 [**24**]	To elicit the health needs of older people in East Lancashire	Twelve participants	• Identify health needs	No evaluation reported
Iliffe 2004 [**25**]	To identify unmet needs among older people	2, 3 (?) participants recruited from local voluntary groups	• Develop postal questionnaire • Facilitate focus groups • Participate in consensus conference	No evaluation reported
Koops 2002 [**27**]	To involve older people in designing information leaflets to improve recruitment and consent procedures in a randomised controlled trail (RCT) for thrombolysis	Fifty four participants (consultation meetings); 19 participants (focus groups); 6 carers and patients from a stroke unit (comment on information leaflets)	• Attend consultation meetings • Review information leaflet	No evaluation reported, but authors report that user involvement led to ethical committee approval of the RCT
Marquis-Faulkes 2005 [**30**]	To develop technology to detect falls in older people	Three focus groups: frail elderly group (aged 70s and 80s); mixed elderly group (aged 65+); retired professionals (aged 75–87)	• View dramatised scenarios based on technical possibilities of the system and discussing these	No evaluation reported
Reed 2002 [**33**]	What developments have taken place in discharge planning in the locality? To explore ways of improving the experience of going home from hospital	One older person was a member of the project team. Other participants' involvement not clear	• Initiate idea for research study • Interview older people • Analyse data • Write/edit reports • Co-author journal article	No evaluation reported
Reed 2004 [**34**]	What issues do older people feel most affects their quality of life in retirement?	One participant	• Initiate research question • Interview older people	No evaluation reported
Ross 2005 [**36**]	To explore older people's expectations, priorities and needs for information in relation to risk of falls	Twenty one older people formed the 'consumer panel' To compare views of older people on risk factors and risk reduction with those of carers and practioners To inform local implementation of Standard 6 of the National Service Framework for Older People	• Designing and managing the project • Analysing data • Disseminating study results	Questionnaire to professionals and users to investigate expectations and impact: • Personal benefit of involvement for older people (e.g. opportunity to learn about falls) • Older people enabled to offer a different perspective to the research

Table 1. (*Continued*)

Study	Research question/objective	Participants	Tasks of participants	Reported evaluation and impact
Seale 2002 [**40**]	To identify and describe nature of indoor mobility related problems and technological solutions to these To propose further research and development of technological products To obtain older people's responses to these proposals	Thirty seven participants aged 70+; 21 participants aged 80+	• Participate in focus groups answering three questions determined by the researchers	No evaluation reported but users identified issues not anticipated by researchers and proposed solutions to problems
Tetley 2003 [**45**]	To explore older people's involvement in decision making	Seven participants as part of an advisory committee	Advise on project—no further details. The focus of article is to describe experiences of involvement	No evaluation reported. Anecdotal evidence of the impact: advice helped researchers to work effectively and positively with different community groups; users benefited socially
Warren 2003 [**46**]	To examine the experiences of women over 50 from a range of ethnic groups on use of health services	Ten female participants	• Interview older women • Identify themes from interview data • Publicise findings	No evaluation reported. The authors report anecdotal evidence of impact on participants: feeling valued, validated and important; building confidence and motivation

trial for acute stroke treatment [**27**]; or consultation as part of the process of seeking approval for research projects by indigenous community groups [**29**]. In all cases the research question remained unchanged after consultation with older people, with the exception of the study on indigenous health where a more appropriate research question was developed after input from an indigenous older person [**29**]. Focus groups were predominantly used to elicit older people's views on the topics concerned.

Data collection and data analysis

Three studies report the involvement of older people in data collection and data analysis [**24**, 43, **46**]: conducting interviews, identifying and discussing emergent themes in content analysis of qualitative data and publicising findings.

Advisory groups

Nine studies involved older people in the research through an advisory group [14, **16**, **17**, 26, **31**, 32, **36**, **39**, **45**, 47]. The principle of the advisory group is to oversee the running of the research project usually from the outset through to the completion of the research. In four cases, as people became more involved in the research, they assumed a more active research role including identifying and discussing emergent themes in qualitative data and interpreting, disseminating and implementing research findings [14, **17**, **31**, **36**].

Project definition to project completion

Seven studies report older people actively conducting research throughout the entire research process: defining the research questions, collecting data, analysing data and disseminating and publicising the findings [**15**, **20**–22, **25**, **28**, **33–35**]. In all the cases, the research was initiated and led by researchers from university departments.

In two of the studies [21, **35**] advisory groups of older people were also established in addition to the research team to oversee and contribute to the running of the project and as 'one way to shift more control' of the research to the older people involved [21].

Barriers and facilitators of involvement

Tables 2 and 3 respectively, list the factors which hindered or helped the involvement of older people in research. Eleven studies did not report any facilitator or barriers [14, 23, **24**, **25**, 26, 32, 37, 38, 42–44, 47].

Impact

Only four studies undertook a formal evaluation of involving older people in the research studies [**17**, 18, **19**, **20**–22, **36**]. Authors of 23 studies commented on the impact of involvement using anecdotal evidence from their experience of involving older people in research. One of these authors acknowledged that formal evaluation was needed [13]. Three studies did not comment on the impact of involvement [37, 43, 44].

Formal evaluation

Formal evaluation focused primarily on the process of involving older people, using questionnaires or focus group

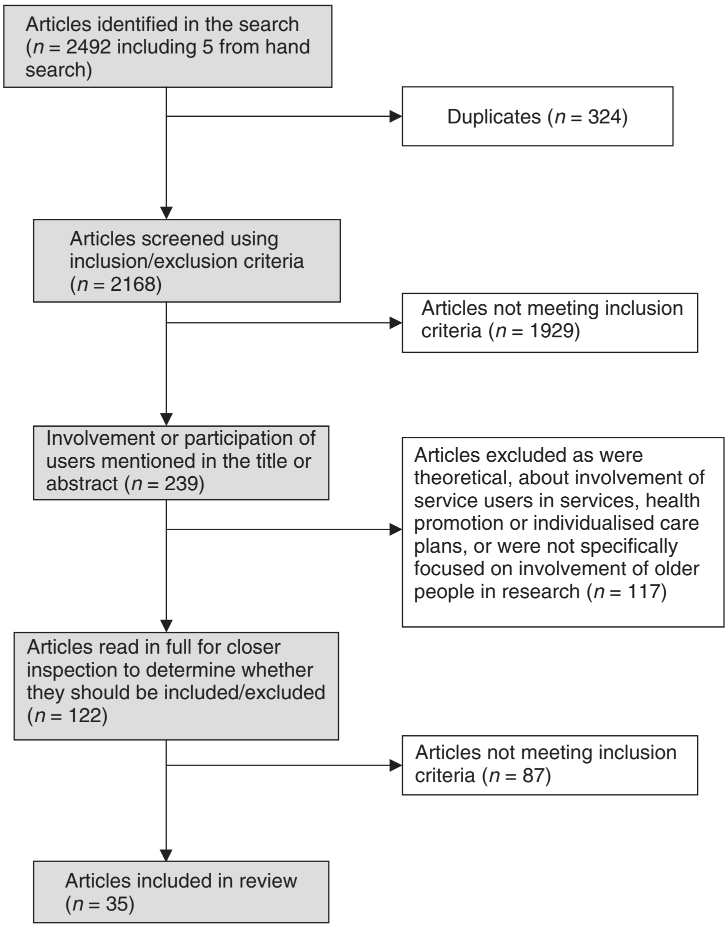

Figure 1. Flowchart of literature search and article selection.

discussions to identify 'top tips' for involving older people in research [**36**] or to determine the levels of satisfaction of taking part in such a process [**17**]. One study that evaluated training courses through informal discussions and questionnaires demonstrated the impact of involvement on participants [**19**]. This included: 'developing a more critical approach; increased confidence, learning to listen to others' points of view; increased awareness of social and political issues; increased ability to confront situations; learning that we are not alone' [**19**]. Dewar [**19**] suggests that the impact of training older people in research can be demonstrated by the kinds of activities older people, having completed the course, are now involved in: working with university researchers to develop research proposals and prioritise the mental health research agenda; and interviewing older people for a research project on healthy eating.

Dickson [**20**] conducted the most comprehensive evaluation using an ethnographic approach. This involved in-depth interviews with 14 of the 25 older women involved in the research and participant observation to determine the impact of involvement on the participants.

There is little evaluation focusing on how involvement has changed the research process or research outcomes although two authors report that involvement in research encouraged participants to become active in their community on issues of relevance to them [**19, 20**]. However, Dickson [22] also reported that the participants' capacity to act as co-researchers was limited by resistance to having to commit to regular meetings of a business or political nature; poor health; unease with working in English or using translators; or unfamiliarity with expressing opinions and beliefs. Part of the evaluation questionnaire used in Ross *et al.*'s study [**36**] assessed the impact of involvement on research from the perspective of those involved. A finding from the questionnaires was that the 'older persons' perspective was seen as essential: 'without the consumers' participation it would not have got off the ground' [**36**].

Anecdotal evidence

Evidence of impact based on authors' reflections or anecdotal stories placed greater focus than the formal evaluations on the impact of older people's involvement on research processes and outcomes. Involvement has an impact on older people through realisation that they can shape public policy [13, 14, 22, **35, 45**]. Participants' contact with local organisations and advocacy groups helps to canvass further opinion, disseminate findings, raise awareness of the project and implement research findings [22, **31, 35, 36**]. Consultation with older people in the design stages resulted

Table 2. Barriers to involving older people in research

Stage in process of involving older people	Barriers	Studies
Recruitment	Certain ethnic groups feel 'over-researched' and have a negative perception of research, therefore reluctant to participate	Dickson 2001 [21]; Dickson 2001 [22]; Warren 2003 [**46**]
Sustaining involvement	Lack of suitable venues: not everyone feels comfortable in religious venues	Warren 2003 [**46**]
	In-house caterers not providing adequate or culturally appropriate food	Warren 2003 [**46**]
	People with hearing problems excluded, despite best efforts	Warren 2003 [**46**]
	Power imbalances—tension, conflicts between users and researchers	McWilliam 1997 [**31**]; Reed 2004 [**34**]
	Service users belief that they cannot make a difference and that nothing will change despite the research occurring	Cockburn 2002 [**15**]; Reed 2002 [**33**]; Warren 2003 [**46**]
	The lack of participation by senior decision makers created tension as the project was not seen to be valued by those who ultimately make the decisions	Reed 2002 [**33**]
Carrying out research activities	Lack of confidence, unfamiliarity with research	Dewar 2005 [**19**]; Dickson 2001 [21]; Reed 2002 [**33**]; Warren 2003 [**46**]
	Ill health, multiple medical conditions, hospital appointments, physical frailty and death meant that users were not always able to complete research tasks	Delgado 1996 [**17**]; Lacey 2000 [**28**]; Dickson 2001 [**22**]; McWilliam 1997 [**31**]
	Communication: language barriers, jargon	Cockburn 2002 [**15**]; Dickson 2001 [22]; McWilliam 1997 [**31**]; Ross 2005 [**36**]
	Tension between users and researchers as to what constitutes a good study or what the purpose of research is—differences between knowledge, experience, researcher/user priorities for the study outcomes and expectations of the research donors	Dickson 2001 [22]; Reed 2002 [**33**]; Roe 1995 [**35**]; Ross 2005 [**36**];
	Time—older people have other commitments contrary to belief that older people's time is widely available	Cockburn 2002 [**15**]; Reed 2004 [**34**]
	Time—user involvement can significantly alter the research timetable	Roe 1995 [**35**]; Warren 2003 [**46**]
	Researchers underestimated people's desire to be more actively involved	Warren 2003 [**46**]
	Researchers overestimate people's capacity to be active co-researchers	Dickson 2001 [22]; Reed 2002 [**33**]
	Resources for user involvement and the need for funding underestimated	Warren 2003 [**46**]

in a number of positive outcomes: one study was accepted by an ethics committee [**27**] and another by an indigenous community board [**29**]. Consultation also led to a more salient study design [**39**], resulted in discussion of issues researchers would not have anticipated [**40**], achieved better recruitment rates [**17**] and facilitated the consent process [**27, 45**].

Authors of studies that did not undertake a formal evaluation also suggested that participants' involvement led to: increased knowledge, awareness and confidence; meeting other people in similar situations; and the therapeutic value of being 'listened to' [**17, 20**–22, **27, 30, 36, 45**].

Discussion

This review has shown that examples exist of older people who have been involved in research beyond providing data for research. Older people tended to be involved in health areas or services specific to older people: stroke; falls; assistive technology associated with decreased mobility; and quality of life as people age. The articles reviewed were published across a broad spread of journals although gerontology and nursing journals dominated.

The involvement of older people in research appears to be a growing phenomenon based on the increasing number of publications each year over the 10-year period reviewed. The growth in recent years was particularly evident in the 11 articles from the United Kingdom, which were all published between 2002 and 2005. The apparent increase is perhaps an artefact of user involvement being topical and therefore publishable but it may also reflect the response of researchers to requests from government and donors to involve participants in the research. The effect of this policy requirement may be further demonstrated by the fact that in almost all the studies reviewed the request for involvement was initiated by university researchers rather than patients demanding to have a role in what is researched and how it is researched.

Our review identified a number of barriers to involving older people in research: cultural divisions; language barriers;

Table 3. Factors facilitating involvement of older people in research

Stage in process of involving older people	Facilitators	Studies
Recruitment	Culture brokers/community guides/personal contacts for recruitment	Crist 2003 [**16**]; Delgado 1996 [**17**]; Manson 2004 [**29**]; Shellman 2000 [**41**]; Warren 2003 [**46**]
	People interested in joining the study if involvement would be worthwhile and research findings would result in change (e.g. in health services, health policy, health inequalities)	Dickson 2000 [**20**]; Manson 2004 [**29**]; Ross 2005 [**36**]; Warren 2003 [**46**]
	Older people already involved recruiting others to be involved	Crist 2003 [**16**]
Sustaining involvement	Personal connections to sustain involvement and remind people of their part in a collaborative group (e.g. 'thank you' notes, telephone calls, Christmas cards, social mornings, newsletter)	Crist 2003 [**16**]; Dickson 2000 [**20**]; Roe 1995 [**35**]; Ross 2005 [**36**]; Warren 2003 [**46**]
	Flexibility of agenda—allowing other issues (outside of the research agenda) to come up and be discussed	Crist 2003 [**16**]; Dickson 2001 [22]; **Ross 2005** [**36**]; Warren 2003 [**46**]
	Time to build up partnerships and trust	Dickson 2001 [22]; Warren 2003 [**46**]
	Commitment and support of the research team to mediate cross-cultural and power imbalances	Cockburn 2002 [**15**]; Dickson 2001 [22]; **Ross 2005** [**36**]
	Training, information, orientation and welcome package	Cockburn 2002 [**15**]
	Ownership—users as chair, university researchers not the sole expert role	**Ross 2005** [36]; Saunders 2003 [**39**]
	What older people get out of being involved—knowledge, sociable aspect, lunch, enjoyment, self-healing/therapeutic value, increasing confidence	Delgado 1996 [**17**]; Dickson 2000 [**20**]; Koops 2002 [**27**]; Marquis-Faulkes 2005 [30]; **Ross 2005** [**36**]; Tetley 2003 [**45**]
	Suitable venues: e.g. accessible for people with disabilities, places people meet on 'own terms', research departments—people liked attending places that are 'usually off-bounds to community groups'	Delgado 1996 [**17**]; Saunders 2003 [**39**]; Warren 2003 [**46**];
	Reciprocity—researchers also giving something back to community they are working in, e.g. researchers providing information on social services	Crist 2003 [**16**]; Delgado 1996 [**17**]; Roe 1995 [**35**]
Carrying out research activities	People welcome the chance to discuss medical and health issues	Koops 2002 [**27**]; Tetley 2003 [**45**]
	Focus groups and dramatisation to stimulate discussions	Marquis-Faulkes 2005 [**30**]
	Focus groups allowed discussion of issues not anticipated by researcher, which were then incorporated in research design	Seale 2002 [**40**]
	Allowing users rather than 'experts' to define the research problem to encourage ownership and participation in the research	Dickson 2001 [22]; Roe 1995 [**35**]

research skills capacity; ill health; time and resources. These barriers do not differ from barriers identified from studies involving younger people [48, 49].

Benefit for research of user involvement

Increasingly in the UK, donors and ethics committees ask researchers to state how they will involve patients and the public in the research process, yet there has been little critical discussion of the reasons for promoting involvement with the general assumption that this is a 'good thing' [50]. Although policy documents justify involvement as a way of improving research and making research outcomes more relevant for the end-users of research, there was little evidence from our review that this has been achieved. This was because very few of the studies undertook any formal evaluation. Where evaluation was undertaken, this focussed mainly on the processes of recruiting and involving older people, or the impact of involvement on participants.

A common outcome of involving older people was the increased political engagement and confidence of older people to critique policies relevant to them. The older people involved often had contacts with relevant organisations which could help to publicise or implement the research findings [**16, 31, 36, 45**]. A number of the authors commented that participants were motivated to be involved because they wanted something (e.g. a service, a policy) to change as a result of the research [14, **20, 36, 46**]: they did not want to be involved in research for the sake of doing research. Being involved in the research enabled or empowered them to feel that they could make this change.

The empowerment of users is promoted as one of the benefits of involving older people, or patients and the public in general, in research [51]. There are many definitions of empowerment. Cheater [52] distinguishes between empowerment defined as access to resources and as a right to express an opinion. It is the latter definition that those promoting user involvement on the basis of empowerment refer to. However, those promoting empowerment through user involvement have yet to demonstrate how user involvement empowers people equitably. A number of the articles reviewed commented on how difficult it was to reach certain groups [22, **41, 46**]. None of the articles in the review reported in detail who the users were, nor did they address the question of representation. The fact that older people in a number of the studies reviewed were able to publicise the research project and findings within their own networks, and advocacy groups suggests that those who decide to participate are those who are already engaged and are, perhaps, the group which needs empowering the least.

Defining user involvement

In undertaking this review, we found that involving people in research can be interpreted in many ways. We used a specific definition of involvement: older people involved in a way that went beyond being subjects of the research. However, for many researchers, involvement meant having participants complete a questionnaire or take part in an interview, particularly if the data involved research subjects' opinions or perspectives. Some of the articles excluded from the review seemed promising from the terminology of involvement used in the title, abstract and introduction, yet upon reading the article in full, no example of actual involvement, beyond older people providing data as research subjects, was reported.

This is a problem caused in part by the lack of definition of user involvement and the myriad of terms used to describe involvement activities: participatory research, collaborative research, user involvement, consumer involvement, participatory action research. It may also highlight the problem of user involvement, promoted as an unclear policy that researchers are expected to undertake. Lack of an agreed definition and clear policy may lead to tokenistic involvement and permit spurious claims of user involvement by researchers to meet and fulfil funding and research ethics committees' requirements [50].

The promotion of an unclear policy further highlights the need to fully understand the impact of user involvement on research. If it can be shown that the involvement of older people (or other population groups) can enhance both research processes and outcomes, researchers may be less inclined to treat user involvement as something they have to do and instead, undertake genuine engagement with older people.

None of the articles reviewed described any failure of involving older people in research although the difficulty of involving users as researchers is acknowledged. This could be a publishing bias: that articles containing negative results are not written or published. It may also relate to the lack of agreed definition and outcomes of user involvement.

Limits of the review

Our review only included studies that involved older people; studies may exist where older people have been involved in research along with younger people. We may also have inadvertently missed studies that may have involved patients or the public, for example, on a project advisory group, but not reported this in their publication of the research. Our study is further limited by restricting our searches to peer reviewed journals. The grey literature, including books and the Internet, may provide additional information about studies that have involved older people.

Conclusion

This review demonstrates that the involvement of older people in research is a growing phenomenon: particularly in the United Kingdom. The barriers to involving older people identified were similar to barriers identified in other reviews or studies involving other patient groups, suggesting that it is not necessarily harder to involve older people simply because of their age. Furthermore, anecdotal evidence from the articles reviewed suggests that older people are interested in research, particularly if it is a means to becoming politically active and aware and the research findings change services or policies.

As other reviews of user involvement have concluded, very little is known about how involvement changes the research process [**7, 8**]. Very few studies in the review performed any formal evaluation. Where evaluations were conducted they tended to focus on the benefits of involvement to those who participated in the research rather than on the benefits for research questions, processes and outcomes. This should be addressed before user involvement is further promoted as a policy.

Key points

- The involvement of older people in health research is a growing phenomenon, particularly in the United Kingdom.
- Factors hindering the involvement of older people in research are the same as reported factors hindering the involvement of younger people, suggesting that age, per se, is not a barrier.

- However, as very few studies undertook evaluation of involving older people in research very little is known about how involvement changes research process, outcomes and quality.

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Conflicts of interest

None declared.

Ethical approval

Not required.

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PLEASE NOTE: The very long list of references supporting this review has meant that only the most important are listed here and are represented by bold type throughout the text. The full list of references is available on the journal website http://www.ageing.oxfordjournals.org/ as appendix 1.

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Appendix XIV: Presentations arising from this thesis

Fudge N. *Patient involvement in stroke research.* Presentation at King’s College London and Guy’s & St Thomas’ NHS Foundation Biomedical Research Forum, London, February 2011.

Fudge N. *An ethnographic study of user involvement in stroke research and stroke service development.* Poster presentation at King’s College London Health Schools Graduate Research Showcase Event, London; July 2010

Fudge N. *Communicating stroke research with stroke survivors.* Paper presented at King’s College London Stroke Research Team lunchtime seminar, London; March 2008

Fudge N, Wolfe CDA, McKevitt C. *The involvement of people with stroke in health service development and health research: an ethnographic study.* Paper presented at King’s College London Health Schools Graduate Research Showcase Event, London; July 2008

Fudge N, McKevitt C. *Involving people with stroke in stroke research – preliminary findings.* Paper presented at King’s College London Stroke Research Team lunchtime seminar, London; January 2008.

Fudge N, McKevitt C. *What shapes and constrains the influence of service user involvement in research?* Paper presented at Authenticity to Action Conference: Involving Service Users and Carers in Higher Education, University of Lancaster; November 2007.

Fudge N. *Having a stroke: what does it cost individuals and families?* Presentation of research results to stroke survivors at Time and Talents Stroke Club, London; July 2007.

Fudge N, McKevitt C. *Involving people with stroke in stroke research: example of cost of stroke pilot study.* Paper presented at the King’s College London Stroke Research Team lunchtime seminar, London; June 2007.

Fudge N, McKevitt C. *User involvement in the King's College London Stroke Research Programme.* Paper presented at the South East Stroke Research Network Annual Meeting, London; May 2007.

Fudge N, McKevitt C. *User involvement in stroke service development: rhetoric and reality.* Paper presented at Guy's, King's and St Thomas' School of Medicine Grand Round, London; October 2006.

Fudge N, Wolfe CDA, McKevitt C. *An ethnographic approach to evaluation of user involvement in stroke service development.* Paper presented at the Society for Social Medicine Annual conference, University of Leeds; September 2006.

Fudge N, McKevitt C. *Involving people with stroke in stroke research.* Paper presented at Involve conference: 'People in Research', University of Hertfordshire; September 2006.

Fudge N, Wolfe CDA, McKevitt C. *Can people with stroke be involved in developing stroke services?* Paper presented at the 15th European Stroke Conference, Brussels; May 2006.

Fudge N, McKevitt C. *Involving people with stroke in research: will it make a difference and how will we know?* Paper presented at invoNET workshop: Researching public involvement in research, London; March 2006.

Fudge, N. *User involvement in stroke research.* Paper presented at the King's College London Stroke Research Team lunchtime seminar. London; February 2006.

Fudge, N. *User involvement in stroke research.* Poster presentation at King's College London Health Schools Graduate Showcase Event, London; July 2005.

Fudge N, Wolfe CDA, McKevitt C. *User involvement in stroke research: rationale, examples and prospects.* Poster presentation at 14th European Stroke Conference, Bologna; May 2005.