

El Enany, Nellie (2013) Service user involvement in healthcare service development: knowledge, representativeness & the 'professional' user. PhD thesis, University of Nottingham.

**Access from the University of Nottingham repository:**

<http://eprints.nottingham.ac.uk/14481/1/602801.pdf>

**Copyright and reuse:**

The Nottingham ePrints service makes this work by researchers of the University of Nottingham available open access under the following conditions.

- Copyright and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners.
- To the extent reasonable and practicable the material made available in Nottingham ePrints has been checked for eligibility before being made available.
- Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.
- Quotations or similar reproductions must be sufficiently acknowledged.

Please see our full end user licence at:

[http://eprints.nottingham.ac.uk/end\\_user\\_agreement.pdf](http://eprints.nottingham.ac.uk/end_user_agreement.pdf)

**A note on versions:**

The version presented here may differ from the published version or from the version of record. If you wish to cite this item you are advised to consult the publisher's version. Please see the repository url above for details on accessing the published version and note that access may require a subscription.

For more information, please contact [eprints@nottingham.ac.uk](mailto:eprints@nottingham.ac.uk)

# **Service User Involvement in Healthcare Service Development**

**Knowledge, Representativeness & the 'Professional' User**

**Nellie El Enany**

**Thesis submitted to The University of Nottingham for the  
degree of Doctor of Philosophy**

**December 2013**

## ABSTRACT

Policy makers have increasingly regarded user involvement as an important dimension of service development. Current government policy advocates the involvement of service users in healthcare service development across all levels of an organisation, ranging from the level of individual service user to the development and improvement of health services (DoH 1992, 1999, 2001a, 2001b, 2003a, 2003b, 2004, 2005a, 2007a, 2007b, 2010a, 2010b, 2011, 2012). This has manifested in the creation of a number of public and patient involvement initiatives including Patient Advocacy and Liaison Services (PALS), Locals Involvement Networks (LINKs), Patients Forums and more recently Healthwatch Organisations. User movements and policy pressures have also led to the formation of user led groups pushing for changes in health and social care. However, these groups often operate on the margins, and as such, lack the legitimacy to work alongside professionals in service development and improvement.

Despite involvement being driven by policy, research suggests that user involvement is often tokenistic, unrepresentative (Contandriopoulos et al. 2004; Harrison and Mort 1998; Rowe and Shepherd 2002) and subject to a selection of those users deemed to be a 'safe pair of hands' (Hogg 1999, p. 100). Furthermore, user involvement has been exacerbated by the 'tick' box culture in healthcare and the growing managerialisation of public services, creating a smokescreen to authentic

user involvement. A recent study (Lakeman et al., 2007) suggests that a hierarchy of service users has emerged based on knowledge and authority in the service user community resembling stratification akin to the profession of psychiatry. This study is a platform for this research which aims to offer empirical analysis to illuminate the processes of stratification which give rise to this hierarchy of service users, which Lakeman et al.'s work suggested existed, but which was not empirically supported. In doing so, discussions centre along three main themes; knowledge, representativeness and the 'professional' user.

Policies on user involvement have led to health organisations developing strategies around involvement where users are involved at all levels of the organisation. As well as these, a plethora of grass roots groups have gained momentum over the past twenty to thirty years (Hogg 1999, p.127) and in recent times with the support of user involvement legislations have gained greater legitimacy amongst professionals. However, organisations are in constant flux and as they become more embedded in the system and established, user-led groups may become 'professional' working closely with 'sympathetic' professionals (Hogg 1999, p.127). By applying theories from the sociology of professions on expert knowledge and jurisdiction in the context of user involvement policy and practice, I describe the processes that lead to the stratification of users and ultimately to unrepresentative involvement.

Using two comparative cases of user involvement, one a top down initiative in mental health service provision and the other a user led stroke group with a focus on stroke service development and improvement, I examine the processes of

involvement that give rise to unrepresentative user involvement. In doing so I hope to contribute to theories on user involvement by illuminating the processes which lead to the stratification of users and unrepresentative user involvement.

The thesis begins by exploring the historic context of public participation and user involvement, the involvement process and debates around representativeness. This framework informs an analysis of rationales for user involvement and the challenges of involving the 'right' user. Using 40 in-depth semi-structured interviews, observations and documentary analysis the study presents insights of various actors' perspectives of the involvement process, non-representative involvement and the professional user.

The remainder of the thesis presents and compares the empirical results from the two cases in mental health and stroke. The study draws on theories from the sociology of professions to highlight the processes which lead to the stratification of service users including their professionalisation. Akin to professionals, users were found to delineate jurisdiction using their expert knowledge and education, gained through the involvement process but also by drawing on their social status and previous professional work.

The theoretical and policy literatures coupled with the empirical findings present a number of tensions. Policy directives on user involvement are awash with ambiguities resulting in different ideas of how involvement activities should be played out in practice. This is aggravated by the increasingly target driven NHS culture, where professionals often choose the easier option and involve those users

who are known to them and who are usually more articulate and able. This results in the repeated involvement of a certain 'type' of user and the marginalisation of other 'lay' users leading to a hierarchy of users where a cadre of professional users dominate the user community casting other 'lay' users as amateurs.

## ACKNOWLEDGEMENTS

I am thankful and extremely grateful to my supervisors Graeme Currie and Andy Lockett for their support, patience and guidance. I will never forget this.

To Andrea Tomlinson who was supportive and encouraging from the very first day of this research and always went out of her way to help.

My dear friend Michael Humphreys, who always listened and provided much needed humour.

To my Father, Ibrahim, who offered his wise words and unwavering support, and who always believed in me. My Mother, Isobel, was a sounding board on many occasions, and a much needed eccentric throughout. My brother Adam for his encouraging words and reminiscing childhood stories. To Ali, my best friend, who was always there when I needed him. My love to my late Grandmother, Nellie, who gave me a quiet space to live and work in. My Grandfather, Thomas, for always checking up on me. To all my friends, near and far, who kept me well-balanced.

Most of all, I am thankful and deeply grateful to all of the participants of this research, for their time and support and who let me into their lives and work.

Funding for this doctoral study was provided by the Economic and Social Research Council.

# Contents

ABSTRACT.....	i
ACKNOWLEDGEMENTS .....	i
LIST OF TABLES .....	vi
LIST OF ABBREVIATIONS AND ACRONYMS.....	vii
CHAPTER 1: INTRODUCTION .....	8
Background .....	8
Research gap and contribution.....	11
Thesis structure .....	16
CHAPTER 2: SERVICE USER INVOLVEMENT IN HEALTHCARE: POLICY AND PRACTICE.....	18
Introduction.....	18
The policy of user involvement .....	20
<i>Consumerism and involvement in the 1990s.....</i>	<i>23</i>
<i>Involvement from 1997 onwards.....</i>	<i>25</i>
<i>User involvement in mental health.....</i>	<i>29</i>
<i>User involvement in stroke services.....</i>	<i>31</i>
The involvement process .....	32



Social movements, user led organisations and the voluntary sector.....	37
Lay experience or expert knowledge .....	41
Representing the user community? .....	48
Representative of whom?.....	58
Summary .....	65
<b>CHAPTER 3: PROFESSIONS AND HEALTHCARE: PROFESSIONALISM, PROFESSIONAL PROJECTS AND EXPERT KNOWLEDGE.....</b>	<b>68</b>
Introduction.....	68
Defining professions .....	70
<i>Professions and professionalism.....</i>	<i>72</i>
<i>Professionalisation and professional projects.....</i>	<i>77</i>
Professions and knowledge.....	82
Professions in healthcare.....	88
Medical knowledge and changes in healthcare.....	90
Summary .....	95
<b>CHAPTER 4: METHODS .....</b>	<b>97</b>
Introduction.....	97
Background .....	98
Qualitative research.....	102
<i>Case study research .....</i>	<i>103</i>

<i>A critical realist approach</i> .....	105
Case selection.....	106
Case specifics .....	108
<i>Mental health case</i> .....	109
<i>Stroke case</i> .....	111
Data collection .....	112
<i>In-depth interviews</i> .....	112
<i>Observations and field notes</i> .....	115
<i>Document analysis</i> .....	116
Data analysis .....	117
<i>Preliminary analysis</i> .....	117
<i>Systematic analysis</i> .....	119
Validity, reliability and reflexivity.....	122
Summary .....	124
<b>CHAPTER 5: USER INVOLVEMENT IN MENTAL HEALTH SERVICE DEVELOPMENT</b> .....	135
Introduction.....	135
Case background .....	136
The involvement process .....	141
<i>The involvement centre</i> .....	142

<i>Training and education</i> .....	147
<i>Recruitment and selection</i> .....	151
Outcomes of involvement .....	157
<i>The professionalisation of users</i> .....	157
<i>Professional jurisdictions defended</i> .....	163
Service user representativeness.....	171
Summary .....	179
<b>CHAPTER 6: USER LED INVOLVEMENT IN STROKE SERVICE DEVELOPMENT</b> .....	182
Introduction.....	182
Case background.....	184
The involvement process .....	188
<i>Creating a user led group</i> .....	188
<i>Constructing identities</i> .....	190
<i>Developing a professional group identity</i> .....	194
Outcomes of involvement.....	198
<i>The professional user</i> .....	199
<i>Professional jurisdictions defended</i> .....	203
Service user representativeness.....	208
Summary .....	216

CHAPTER 7: DISCUSSION.....	219
Introduction.....	219
The involvement process .....	220
<i>Selection and self-selection</i> .....	224
The stratification of users.....	227
<i>Lay expertise or specialist knowledge?</i> .....	228
<i>Professional jurisdictions defended</i> .....	232
Outcomes of involvement .....	239
<i>The 'professional' user</i> .....	240
<i>Representative involvement achieved?</i> .....	248
Conclusion .....	253
CHAPTER 8: CONCLUSION.....	258
Introduction.....	258
Theoretical contribution.....	259
Implications for practice and policy.....	262
Limitations of study and future research.....	265
References .....	272

# **LIST OF TABLES**

Table 1: Mental health case: Role descriptions .....	125
Table 2: Mental health case: Interviewees and backgrounds.....	127
Table 3: Mental health case: Interviewees and backgrounds (service users and carers) .....	129
Table 4: Stroke group: Interviewees and role description .....	133

# **LIST OF ABBREVIATIONS AND ACRONYMS**

ADHD	Attention-Deficit Hyperactivity Disorder
AIDS	Acquired Immunodeficiency Syndrome
CAS	Complaints Advocacy Service
CHC	Community Health Council
CCGs	Clinical Commissioning Groups
DoH	Department of Health
EPP	Expert Patients Programme
ESRC	The Economic and Social Research Council
GP	General Practitioner
HIV	Human Immunodeficiency Virus
INs	Innovation Networks
LINK	Local Involvement Network
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NPM	New Public Management
PALS	Patient Advocacy and Liaison Services
PCT	Primary Care Trust
PPI	Patient and Public Involvement
SHA	Strategic Health Authority
UK	United Kingdom

## **CHAPTER 1: INTRODUCTION**

### **Background**

Current government policy in England advocates the involvement of services users<sup>1</sup> from the individual level of care to the development and improvement of health services (DoH 1992, 1999, 2001a, 2001b, 2003a, 2003b, 2004, 2005, 2007a, 2007c, 2010a, 2010b, 2011, 2012). As part of this, we observe specific user involvement initiatives, such as Patients Charter (DoH, 1991), The NHS Improvement Plan: Putting People at The Heart of Public Services (2004) and the development of local involvement networks (LINKs). More recently, a Government White Paper in England, 'Equity and Excellence: Liberating the NHS' (DoH, 2010) emphasises 'shared decision-making' between professionals and users necessary in the development and delivery of healthcare. This has manifested in the creation of a number of public and patient involvement initiatives, including Patient Advocacy and Liaison Services (PALS), Patients Forums, Local Involvement Networks (LINKs) and more recently Healthwatch Organisations. In recent times as part of the Conservative Party's agenda on the Big Society there has been an emphasis on communities and the public to have a say in public services and community matters (David Cameron's Big Society speech, 2009).

---

<sup>1</sup> Service users are given numerous names including; clients, citizen participants, users, carers, consumers, lay people, survivors, service user and research partners or associates (Buckland et al., 2007). In this work service user is used to describe those who have received mental health services for their condition and in most cases still do. In the stroke case I used stroke survivor and service users interchangeably to describe the participants of this study who experienced stroke, received stroke services and continue to do so. The name service user and stroke survivor or conqueror differs because of the different health settings, different organisational settings or users' preferences.

User involvement has been influenced heavily by social movements, predominantly the disability movements and mental health survivor movement (Rogers and Pilgrim 1991; Weinstein 2010). Driven by democratic and technocratic rationales for involvement, where the public are seen to have a vested interest in service provision and where their experiential knowledge is seen as valuable in the development of services, user involvement is now mandated by policy under the Health and Social Care Act (2011). Similar initiatives of public involvement are evident in much of the developed world (Kling et al. 2008; Lawrence 2004; McCann et al. 2006; Middleton et al. 2004; Nestor and Galletly 2008) including the United States (Potter, 2010), Australia (Happell and Roper 2006), Denmark (Blaauwbroek 2002) and Canada (Fooks 2004).

Despite user involvement being driven by policy, research suggests that user involvement is often unrepresentative, tokenistic and often not realised in practice. Furthermore, user involvement has been exacerbated by the 'tick' box culture in healthcare and the growing managerialisation of public services, creating a smokescreen to authentic user involvement. Through a process of self-selection by those wanting to be involved (Church et al., 2002) and selection of those who are easiest to involve by those controlling the involvement process (Harrison and Mort, 1998) to legitimate their own interests (Contandriopoulos et al. 2004; Harrison and Mort 1998; Rowe and Shepherd 2002) service users struggle to assert authoring over professionals in service provision (Hodge, 2005). Consequently a paradox arises where professionals involve a user who is articulate and educated (Learmonth et al.,



2009; Martin 2008a, 2008b), representing a 'safe pair of hands' (Hogg, 1999: 100) but who is often unrepresentative of the user community.

Added to this, there is growing rhetoric around lay expertise and lay knowledge with what constitutes credible 'expertise' not being entirely clear (Collins and Evans, 2002). While user involvement is seen as a mechanism to capture users' experiential knowledge of illness and of health services this is not always inputted into the service improvement and development because professionals dominate and control involvement processes. Those who are involved, and perceived by professionals as the 'right' users are those users who possess other skills and 'alternative expertise' (Potter, 2010) making them attractive to professionals. In acquiring different types of knowledge, predominantly scientific knowledge, a divide between users occurs where some are seen as 'lay lay' users and others as 'lay experts' (Elbaz, 1992). This latter point however is only made latterly in a number of studies (Elbaz 1992; Epstein 1995, 1996; Potter 2010; Thompson et al. 2012) or not empirically supported (Lakeman 2007). It is also unclear exactly what forms of knowledge users contribute to the involvement process, how this knowledge is acquired and whose interests are being served through the input of this knowledge into processes of involvement.

Lakeman et al. (2007) suggest that there has been the creation of a hierarchy of users based on knowledge and authority in the service user movement which has led to some users gaining more privileged positions than others. One of the problems with this Lakeman et al. (2007) suggest is that the stratification evident in the profession

of psychiatry is being mirrored in the user community, where certain users are claiming superior positions of power and status and where legitimacy is rarely challenged. The study however does not describe the processes leading to the stratification of users and is not empirically supported.

Stratification such as this is also evident in professions such as law and medicine where professions will mandate expert knowledge for political mobilisation and authority (Halliday, 1987). The process of professionalisation describes how professionals seek to create and control areas of the market by using their skills and expert knowledge to secure and control social privileges (Larson, 1977). This expert knowledge (Macdonald, 1999) enables professions to delineate jurisdiction and serves as the basis for professional identity and political control, ultimately enabling them to differentiate themselves from other occupational groups wishing to compete with them (Abbott 1988, 1995). For those users who are involved in managerial controlled involvement activities often lack the legitimacy and power of user led user groups and social movements. These users have to then construct a professional identity for themselves to provide them with the credibility to work with health professionals and managers. How they construct a professional identity using expert knowledge and seek to stratify themselves from other 'amateur' users is an area which this work seeks to shed light on.

### **Research gap and contribution**

While studies highlight the plethora of difficulties of involvement in practice ranging from professionals dominating the process to select users being involved, it is less

than clear what occurs during the involvement process. That is, why are certain users chosen over others, what skills or knowledge do these users possess? There is the assumption that those users perceived as the 'right' users are involved to serve professional interests and legitimate decision making but are these users' interests too being served in any way? While Lakeman et al., (2007) suggest there is a hierarchy of users who make claims to knowledge and authority mirroring professions such as psychiatry, this is not empirically supported and the processes behind this stratification are not identified. Using expert knowledge do users in the same way as occupations such as law and medicine construct a professional identity for themselves in a pursuit for status and authority? Policy on user involvement, studies on user representativeness and how involvement is enacted in practice, debates around what constitutes lay expertise and knowledge, and a need to examine the processes leading to the stratification of users, led to the aim of this thesis, that is, to examine the processes of user involvement that give rise to the paradox of unrepresentative involvement.

Using two comparative cases of user involvement, one in mental health and the other in stroke service development and improvement, I set out to explore the processes of user involvement in practice along three main themes; knowledge, representativeness and the 'professional' user and illuminate how they differ and are similar across both cases in the discussion chapter. By considering these processes and the interactions between different service users and professionals I seek to add to existing studies of user involvement. While there are a number of studies examining how and if user involvement contributes to health service development and improvement and the

tangible effects of this (Crawford et al. 2002; Simpson and House 2002), this thesis does not seek to answer such questions or contribute to these studies. Instead, it seeks to provide two examples of user involvement and consider questions about the processes of involvement to examine the dynamics of the interactions between the various actors in the involvement process, the stratification of users and the processes that lead to unrepresentative user involvement.

While the overarching aim of this thesis is to examine the processes of user involvement which give rise to unrepresentative involvement, in light of the literature review and preliminary field work, two broad research questions are posed:

R1. What are the processes leading to the stratification of users?

R2. What are the outcomes of involvement processes?

The first research question aims to examine the processes of involving users during user involvement processes and activities. That is, the processes by which users are selected or self-selected by professionals and which users are involved. The second research question, explores the outcomes of the involvement process where users were selected or self-selected for involvement activities. Rather than measuring or following user involvement in a specific service improvement or development and the outcomes of this on health services, this work addresses the sociological implications of the involvement processes that led to the stratification of users and the professionalisation of certain users. I discuss the effect this had within the user community and discuss it in the context of representative user involvement.

Drawing on two cases of user involvement, one a top down initiative in mental health and the other a bottom up user led initiative in stroke, I attempt to make a theoretical contribution to our understandings on how user involvement is enacted and becomes unrepresentative. The first case, is a top down initiative in a mental health Trust. As a response to policy imperatives around user involvement the Trust sought to involve users in a range of involvement activities after being trained at an involvement centre internal to the organisation. In doing so, certain users were selected for training activities while others were seen as less suitable.

Following the training and education, certain users were self-selected or picked by health professional and managers from across the Trust for involvement activities. Through repeated involvement, knowledge and education from training through involvement, and from their previous careers a certain cadre of users sought to carve out jurisdiction using a combination of their pre-existing and acquired knowledge coupled with their skills to work with managers and health professionals. Over time, this led to the marginalisation of 'lay' users and the domination of the user community by 'expert' users who served professional interests and sought to use involvement activities and work alongside professionals as a mechanism to advance their own professional user careers and gain professional user status.

The second case, was one of a user led group run by retired stroke survivors who had all occupied senior management positions before their stroke and sought to use their group as leverage to improve stroke services. Formed and led by a charismatic and educated stroke survivor, the group were repeatedly used for involvement activities and often were self-selected, aware that other groups would not be able to contribute

to management meetings and professional work in the same way. Although the group had exerted positive influence in stroke services over the years, the repeated pattern of selection and self-selection led to other user voices being absent. Rather than being professionalised through the involvement process, as were the users in the mental health case, this group of users identified themselves as professionals in that they had all occupied senior management positions prior to having stroke, were educated and articulate, therefore mirroring the professional backgrounds of those health professionals and managers they often worked with. Using their knowledge and skills from their past professional careers, the group positioned themselves as a professional user group able to work effectively alongside health professionals and managers.

The skills and knowledge this group brought to involvement was not necessarily that of knowledge of stroke services and experiential knowledge of the condition but more importantly it was the ability to work alongside health professionals and managers and knowledge of management process. Consequently, this led to these users making claims to expert knowledge and jurisdiction describing other users as being unable to carry out the work they did and ultimately leading to unrepresentative involvement.

By considering these questions and the processes of user involvement in these two cases, I seek to contribute to the literature by explicating the processes through which by a combination of self-selection by those wanting to be involved, and

professionals actively selecting, educating and socialising certain users, unrepresentative involvement occurs. Both the selected users, and the professionals, were complicit in the processes which led to certain users attaining a professional or consultant status by delineating a distinctive body of 'expert' knowledge that bound their jurisdiction providing them with a professional identity, status and authority, and from which they excluded those they perceived as amateur or 'lay lay' users.

### **Thesis structure**

The thesis is structured as follows:

Following on from this chapter, the next chapter explores the historic context of user involvement, the involvement process, debates around what constitutes lay expertise and user representativeness. This framework informs an analysis of rationales for user involvement and the challenges of involving the 'right' user. Chapter 3 reviews the literature on the sociology of professions including professional projects, professionalism and professions in healthcare. The review of this literature serves to inform the literature on user involvement by offering insights into how service users in the same way as professionals become professionalised, how and why they claim jurisdiction and engage in their own professional projects using their expert knowledge while casting other users as amateurs.

Following on from the literature review, Chapter 4 describes the qualitative approach adopted including interviews, observations and documentary analysis. It also

describes the empirical field and the participants. Chapter 5 examines user involvement in a mental health initiative where users were trained by managers to equip them for involvement activities. Over time, and akin to professionals, a certain group of users were found to delineate jurisdiction using their expert knowledge and education while casting other users as amateurs who were unable to be involved alongside professionals. Chapter 6 examines a bottom up user led group where all users in the group were educated and middle class and used this cultural capital to construct their group as a professionally led group. Professionals used the group because they were known to stroke services but also had sufficient experiences and knowledge of the system. The group was also complicit in practices of unrepresentative involvement claiming that other users did not possess the knowledge or skills that their group did. Chapter 7 provides a comparison and discussion of the empirical chapters, considering the findings in the context of existing studies before the thesis is concluded and summarised in chapter 8, noting its limitations and suggestions for future research.



## **CHAPTER 2: SERVICE USER INVOLVEMENT IN**

### **HEALTHCARE: POLICY AND PRACTICE**

#### **Introduction**

Service user involvement has become an increasingly prominent policy aim of healthcare across much of the developed world (including Canada, the United States, England), where users are to be involved at all levels of the organisation from strategic planning to service development (Pyke et al., 1991). For example, representative service user involvement is enshrined in the policy of the National Health Service (NHS) in England, where policy outlines that users should work with health professionals to improve services and transform the inherent professionalised culture within the NHS (DoH 2003a; DoH 2010a). The aim of service user involvement is to counter the traditional power imbalances between providers and service users (Harrison and Mort, 1998), and improve accountability through better representation of service users' needs (Abelson et al., 2003) using their experiential knowledge of the illness.

Although a policy 'ideal', the enactment of representative user involvement may be considered to be paradoxical in nature. Policy promotes 'lay' involvement in service development, but enacted user involvement tends to be un-representative, and consequently tokenistic in nature (Crawford et al., 2003). International studies on user involvement also report shortcomings in its implementation with variable levels of health professionals' support for user involvement with many inclined to exhibit a

tokenistic response towards involving users and negativity from healthcare professionals (e.g. studies in Australia - Happell and Roper 2006; McCann 2006; in Canada – Fooks 2004 and in Denmark – Blaauwbroek 2002). Academic commentators have highlighted that users are commonly unrepresentative, and that they have struggled to assert any authority over professionals delivering healthcare (Hodge, 2005). While user involvement spans a range of levels (Arnstein, 1969) overall, attempts to create a user-led health service have been presented as largely unsuccessful (Beresford 2001; Harrison and Mort 1998; Simpson and House 2002) with a relatively low level of participation and thus has not led to organisational change as a result of significant user involvement (Carr 2004; Hodge 2005).

A number of studies discuss what knowledge ‘lay’ users bring to participative forums and involvement activities suggesting that this may be experiential knowledge of having the illness or scientific knowledge of the illness. There have been suggestions that ‘additional skills’ are required from users suggesting that the idea that involvement can ever be representative is unrealistic. Studies have described how a hierarchy of users or different users exist (Lakeman et al., 2007; Thompson et al., 2012) where differences between ‘lay lay’ users and ‘lay expert’ users emerge (Elbaz, 1992). Unclear however is how and why certain users or activists (Epstein 1995, 1996) become ‘lay experts’ (Elbaz, 1992), how knowledge impacts on jurisdiction, the user identity and on the wider user community and more importantly the processes behind these stratifications.

Through a review of service user involvement literature this chapter draws out how this paradox arises by reviewing current policies on user involvement and the rationales and processes of involvement. This chapter is structured as follows. First, a historical perspective of user involvement and current policies that promote user involvement in the NHS are examined including involvement in mental health and stroke because of their relevance to the empirical field. Second, studies on the involvement process are reviewed. Third, social movements and user involvement in user led organisations are considered. Fourth, notions of lay expertise are considered including the different forms of knowledge lay users contribute. Fifth, debates on service user representativeness and the paradox of involving the 'right' users are examined. The chapter concludes with a summary of the central themes.

### **The policy of user involvement**

As noted in the introduction of this thesis involving the public in service development improves accountability and allows for the representation of the public's views and needs. Involvement may ensure that the managers and healthcare professionals; i.e. the elites of the system, are made accountable to the public in their decision making (Milewa et al. 1999; Williams-Jones and Burgess 2004). Involvement also seeks to address power imbalances by ensuring that professionals take user's views into consideration and are orientated towards the needs of the public or of a particular marginal group in society (Harrison and Mort 1998; Macdonald 2003). Technocratic rationales for involvement suggest that the

knowledge and experience of the public or their ‘uncertified expertise’ (Collins and Evans, 2002) is a distinct lay input in health provision.

Patient and public involvement has been recognised as having numerous benefits including, safeguarding public interests, bringing additional skills to meetings and committees (Hogg and Williamson, 2001), improved information for patients and changes in service provision (Crawford et al., 2002). Democratic rationales for involvement view involvement as a ‘good thing’ (Abelson et al., 2003) and is seen to improve the quality of the service provided (Crawford et al., 2002). Tensions therefore may arise between democratic rationales for involvement where large groups of the public are involved and technocratic rationales where expertise and knowledge of the lay user are required (Martin, 2008a). Although technocratic arguments for involvement depend on the breadth of participation in the same way as democratic rationales, technocratic rationales call for the narrowing of involvement on the basis of expertise (Collins and Evans, 2002). In a later section, I consider how such tensions are evident.

With its origins in socialist political philosophy; consumerism and mental health activism, the survivor movement, user involvement and patient engagement has increasingly become vehicles for a more patient focused health service in the twenty-first century and a central drivers for patient protection in healthcare, service improvement and professional accountability (Greenhalgh et al., 2011). England provides an exemplar of policy efforts to drive user involvement in public service development, including healthcare (Crawford et al., 2002). From an international

perspective, similar initiatives are evident in the United States (Potter, 2010), peer support workers (Nestor and Galletly, 2008) and carer consultants as employees (Kling et al., 2008) in Australia. The latter developed consumer consultants in mental health services and was implemented to draw in consumer perspectives into mental health (Happell and Roper 2006; Middleton et al. 2004). However, the Department of Human Services did not require them to be representative of consumers and employed on the basis of their experiential knowledge of the mental health system (Happell and Roper, 2006) and had a range of personal, organisational, consumer and carer gains (Lawrence 2004; Kling et al. 2008). However, overall the policy ideal of user involvement has proved problematic (Beresford 2001; Harrison and Mort 1998).

The 1960s and 1970s were an important period in the growth of interest in user involvement. This period was regarded as a time of political, cultural and social change and volatility which saw citizen movements who were dissatisfied with their social status promoting public resistance to major social institutions (Mullen and Spurgeon, 2000). This extended to the health sphere and as a result, users sought to challenge service provision which they viewed as dominated by professionals who disregarded the interests and views of users (Irvine, 2002). The emergence of user groups represented a challenge to the NHS which assumed that only professionals possessed knowledge of health provision.

Numerous studies highlight the growing trend of governments to encourage service user involvement in healthcare planning, decision making and policy making (Bowl 1996; Charles and DeMaio 1993; Coney 2004; Crawford et al. 2002; Gregory 2007).

Tracing the trajectory of policy in the realm of service user involvement in England, we observe that interest grew in the late 1960s and early 1970s. Community Health Councils (CHCs) were established in 1974 to provide a voice for patients and the public in the National Health Service (NHS) in England and Wales to ‘represent the interests of the local community’ (Hogg, 1999). They were the main mechanism for involvement but were eventually abolished in 2003 following mixed reviews (Hogg, 1996) where CHCs were seen as a consumerist model of health provision. That is, an approach that is service led and uses consumer involvement to enhance and increase market competitiveness and where market forces take priority over political and democratic engagement and consultation of the public.

### *Consumerism and involvement in the 1990s*

The 1980s and 1990s saw a succession of policy papers advocating a more consumerist approach to healthcare. These included the Griffiths Report (1983) under Conservative rule which introduced the idea of ‘satisfied customers’. The 1990 NHS and Community Care Act was symbolic of the reforms to public service provision prescribed by new public management and outlined patient involvement in key documents including ‘Local Voices: The Views of Local People on Purchasing for Health’ (DoH, 1992).

The United Kingdom has seen a raft of policy initiatives over the years advocating and now legislating the involvement of users in health and social care. The renewed impetus for patient and public involvement in the health sector saw the introduction

of the NHS internal market in the early 1990s and the move from 'patients' to 'consumers' or 'customers' of health service, linked to the cultural and political changes in the health sector (McIver and Brocklehurst, 1999). The consumerist model of health provision was reflected by the 1990 NHS and Community Care Act, which, in its rhetoric, emphasised that users were not merely 'passive' patients, but more 'active' consumers of healthcare (Hogg, 1999). The concept of the 'consumer' was extended into public services providing legitimacy to users whereby encouraging a model with competing interest groups to drive up service standards through the marketization of services (Fotaki 2011; Le Grand 2003).

Public services were seen to be more efficient and consumer orientated moving the power to the public and away from professionals with the aim of reducing the inflexibility and domination of a monopolistic state (Martin et al., 2004). This provider-consumer relationship required the involved user to be a consumer representative explaining what patients and the public wanted from healthcare services (Milewa et al., 1998). However, this created a tension for managers who were faced with addressing cost effective decision making while at the same time satisfying consumer demands (Anderson and Gillam, 2001). The internal market forces aimed to promote and drive the consumerist approach to involvement in the NHS, negated its very intension of driving up the standards of services and were being faced with the managerialist reforms to the NHS and the needs of those involved.

The consumerist model of involvement in the 1990s saw specific user involvement initiatives, such as in Patient's Charter introduced by the DoH in 1991. This approach itself however posed questions about the role of the public and the tensions between new public management reforms and authentic involvement where the client or consumer was seen as a passive voice in service provision (Vigoda, 2002). This approach to involvement was present under Conservative rule prior to 1997 where they sought to create internal market competition to drive up healthcare provision. Labour's approach was based on ideas in favour of citizenship and community where service users and professional worked together in partnership to provide the public with more consumer focused and efficient healthcare.

### *Involvement from 1997 onwards*

The relationships in society between citizens and the state transformed over time and many writers consider involvement predominantly since 1997 in terms of recasting the relationships between the active citizen and the expert authority (Chandler 2001; Clarke 2005). Public participation and involvement can be seen as symptomatic of a managerial political system which seeks to engage with the public to regain political legitimacy by being seen to empower the public but only in on its own terms and within certain boundaries. Rather than 'the people' being 'partners' of professionals, democratic involvement is instead a way of activating, empowering, responsabilising the citizen and then abandoning them to the free market (Clarke, 2005).



New Labour's approach saw the modernisation of the state to align with demographic, cultural and economic changes in society (Newman, 2001) to create a relationship between the citizen and state (Chandler, 2001). On this basis Labour viewed the active citizen as central to the government's strategy for 'democratic renewal' and the 'modernisation' of public services (Gustafsson and Driver, 2005: 530). Patient centred care was essential to the modernisation with the Health and Social Care Act (2001) placing a statutory duty on all NHS trusts, primary care trusts (PCTs) and strategic health authorities (SHAs) to consult and involve patients on the provision and planning of local health services. Moving into the twenty-first century, The NHS Plan: a plan for investment, a plan for reform (2000), was a key driver for the government's modernisation strategy for the NHS which saw the redesign of the health services around the needs of patients.

As part of the government's efforts to roll out the changes outlined in policy, including public involvement, a number of individual consumer focused initiatives were created including Expert Patients Programme (EPP), Complaints Advocacy Service (CAS) and Patient Advice and Liaison Service (PALS), Patient and Public Involvement Forums. These initiatives were mechanisms to give the public a voice where 'patients are seen as active partners in their care' and involved in 'in the design, delivery and development of local services' (Department of Health, 2001).

A range of alternative forums and bodies were established following the abolition of Community Health Councils in 2003. These included Patient and Public Involvement (PPI) Forums which were located in each NHS Trust and Primary Care

Trust and were in charge of reviewing and monitoring services ensuring that patients and the public were involved in service planning and development and were given the power to have access to information. Primary Care Trusts (PCTs) are at the forefront of the reorientation of the NHS and are legally required to involve the public, including service users, patients and carers, in the development of services and in all areas of service delivery. Foundation Trusts also focus on ‘decentralisation and democracy’ (Klein 2004; 2006) and involve local people on their boards who are entitled to take part in voting and are in effect legal owners of the Trust.

In 2006, the government launched The Local Government and Public Involvement in Health Bill in the House of Commons, becoming The Local Government and Public Involvement in Health Act in 2007, which introduced Local Involvement Networks (LINKS). In 2007 following the Local Government and Public Involvement in Health Act (2007), PPI forums were replaced with Local Involvement Networks (LINKs) with the aim of bringing together various public involvement initiatives. These were intended to bring healthcare services closer to local communities and to create a more customer focused service. Local authorities across the country were funded in order to ensure that arrangements were made to establish a LINK in each area and improve healthcare services and the relationships with local communities (DoH, 2007c).

Across the public sector individuals or representatives of communities, citizens and users were incorporated into governance (Barnes et al., 2003) through partnerships and collaboratives rather than through a consumerist model of competition (Newman

et al., 2004). From this perspective, involvement was seen in terms of a partnership and collaborative between users and professionals rather than through consumerism. Labour's modernisation agenda was about 'active citizenship' where citizens have a voice and choice about 'independent agents, rather than dependent subjects waiting on the state's whims.' (Clarke, 2005: 450). These range of involvement initiatives invoked various rationales for involvement by the state. Members of the public were to be randomly selected from those who had responded to Trust surveys and selected through representatives from voluntary organisations to ensure a broad representation of the wider public. This process ensured that the public would be represented in service provision from 'a health service that responds to patients and carers; and a sense of ownership and trust' (Department of Health, 2003a: iii).

Commentators have found that the new public management approach constrained involvement with top down management pressures and a target driven culture with citizens being marginalised (Rowe and Shepherd 2002; Tritter et al. 2003). Despite this shift of discourse from consumerism to communitarian since 1997, studies emphasise the continued consumerist ideology with managers adopting the new public management approach to public involvement. For example, under new public management, involvement is seen as a tool for gathering information on patient views to increase the responsiveness of services rather than as a means of empowering users in decision making (Rowe and Shepherd, 2002).

A Government White Paper in England, 'Equity and Excellence: Liberating the NHS' (DoH, 2010a) emphasises that 'shared decision-making' between

professionals and users is necessary in the development and delivery of healthcare. More recently, the government published 'Liberating the NHS: No decision about me, without me' (DoH, 2012) a government white paper detailing the importance of placing patients' needs, wishes and preferences at the heart of clinical decision making. This vision is emphasised and articulated by the Secretary of State for Health at the time, Andrew Lansley, in the phrase 'nothing about me, without me' an adaptation of the phrase 'Nothing about Us Without Us'; a term adopted by the international disability movement (Barnes and Cotterell, 2012: 3).

Following the creation of the coalition government in 2010, as part of the Health and Social Care Bill from April 2013, Local HealthWatch organisations will be established to continue the current functions of Local Involvement Networks (LINKs), which will be abolished. HealthWatch organisations will continue to function like LINKs and involve and engage local people in health services providing care to service users described as 'citizen's advice bureau for health and social care' (Barnes and Cotterell, 2012: xviii). We observe ongoing official initiatives and strategies by the DoH to promote public involvement in service provision and what was once seen as radical in the 1980s is now embedded in the health and social care system.

### ***User involvement in mental health***

Over the past 20 years the disabled peoples' movements has promoted the understandings and adoption of the 'social model of disability' (Morris, 1998) influencing thinking and understanding in mental health. The roots of user involvement can be traced back to the late 19<sup>th</sup> century, however it was not until the

1980s that voices of protest became more recognised as user movements, forums and groups, including patients councils, user-self-help groups and advocacy groups, commonly created as formally organised networks (Weinstein, 2010). In response, the government began to develop policies for legitimate user involvement.

Guidance documents by the Department of Health, including 'No Health without Mental Health' (2011), encourage service user involvement thereby aiding the recovery of users. The latter sets out six objectives to improve mental health, supporting the Government's aim of providing high quality services for people with mental health problems. User involvement is encouraged in documents, such as, Working in Partnership (DoH, 1994), Building Bridges (DoH, 1995) and The National Service Framework for Mental Health (DoH, 1999). More recently, the Coalition government's white paper, 'Healthy lives, healthy people: our strategy for public health in England' (DoH, 2010b) recognises mental health to be a key public health issue and recent government guidance, 'No health without mental health: a cross-government mental health outcomes strategy for people of all ages' (DoH, 2011), set out a strategy to improve the mental health and well-being of the nation.

In mental health settings, user involvement is questioned because of the nature of the illness and therefore the perceived impact users' mental health has on their decision making (Myers and Macdonald, 1996). Professionals argue psychiatric patients are continually irrational and incapable of providing a valid view in the decision making process (Crawford, 2001) enabling professionals to reject their views if they do not support professional interests (Rogers et al., 1993). Mental illness can therefore be

regarded as unique in that service users may be perceived as too 'mad' to be involved with the associated stigma having profound implications for their involvement.

### *User involvement in stroke services*

Stroke services, from long term to acute care, have been criticised for failing to meet the needs of patients and their families (National Audit Office, 2005). In 2007, the Department of Health published a consultation on a national strategy. The Stroke Association, a charity concerned with combating stroke, campaigned with stroke survivors and carers and responded to the stroke strategy with the 'Five demands for action: The Stroke Survivor's View'. As a result of this, the Department of Health published the National Stroke Strategy (2007b) providing a framework to improve stroke services and provide guidance and support to healthcare professionals, strategic health authorities and patients and their families. Since the stroke strategy and the national awareness of stroke and campaigning for improving services, stroke has become a priority in health provision.

Despite the severity of stroke and its impact on patients and carers (Low et al. 1999; Wolfe 2000), user involvement in stroke is only now beginning to emerge (National Audit Office, 2005) in the United Kingdom (Fudge et al., 2008). Although there are a number of stroke organisations including the charities The Stroke Association and The Stroke Network, patients with stroke have historically not been as organised into grass root movements and activists such as in other health areas including maternity services, mental health and HIV/AIDS (Brown and Zavestiski 2004;

Brown et al. 2006; Fletcher 2003; Kolker 2004). In part, this could be attributed to the population stroke affects that being a higher proportion of older people and those with disabilities (Wolfe, 2000).

### **The involvement process**

Despite policy initiatives, commentators have been critical of the progress in user involvement, pointing out the risks of tokenism and the suppression of users' views (Rhodes and Nocon, 1998). Evidence has highlighted that user involvement can improve health outcomes (Crawford et al., 2002) but the diverse methods of involving users has made it difficult to assess the overall impact user involvement has had across healthcare (Greenhalgh, 2011; Mockford et al. 2012). In addition, the term service user has been contested and there remains stark differences of how PPI in practice is conceptualised and practiced (Mockford et al. 2012) often leading to tokenistic user involvement. In practice however it ought to be considered as a mechanism to generate public value and legitimacy (Tritter and Koivusalo 2013). While a service user may be 'any person who has, is, or may in the future access NHS or independent sector health services' this has been challenged because it sees service users as presenting people in a consumerist or passive way rather than as active participants in decision making (Beresford, 2005).

The implementation of patient and public involvement has proved multi-faceted and problematic because of hierarchical power structures, negative professional attitudes (Farrell and Gilbert 1996), an unsupporting NHS culture (Brown, 2001), a lack of resources and training and institutional practices and contexts which may all affect

the impact service user involvement will have (Greenhalgh, 2011) and the extent to which service users can influence change (Carr, 2007). In a review of the history of user involvement Williamson (2004) suggests that although users are involved in a range of activities and at various organisational levels, there is still a challenge in making choices about their own treatment and care. He explains that this may be due to a lack of government initiatives and messages being filtered down to lower levels such as to the service level. The marginalisation of users, the lack of communication and the cost of involvement, along with professionals who are resistant to change and who attempt to disempower and demoralise service users, all contribute to the challenges of effectively involving users.

In a systematic review of involving patients in the development and planning of healthcare, Crawford et al. (2002) found that services which considered the views and needs of service users contributed to changes across a range of different services. These changes included initiatives to improve access to employment, improved accessibility, crisis services and complementary therapies. Crawford et al. explain that despite patients contributing to the planning and development of services the actual effect this had on the 'quality and effectiveness' of services was unknown. The systematic review also highlighted that service providers must place users in a more influential position in the decision making process for service development and planning so that this can then produce a much needed evidence base.

Studies have found that although service users are involved in service development and that this has contributed to change in varying degrees, ultimately choices and decisions remain in the control of service providers rather than service users (Rutter



et al., 2004) with the interpretation of involvement and ways users are involved are determined by professionals (Daykin et al. 2004; Hodge 2005; Milewa 1999). Rutter et al.'s study carried out in two mental health Trusts in London, identified two key findings; service users or patients wanted to help to bring about changes in policies and in the services provided but they also wanted to improve the conditions and status of people with mental health problems. Despite this, the power to implement change remained with service providers who controlled decision making expecting service users to work to the Trust's ways of working including Trust agendas and management practices. Professionals may then deploy strategies such as using superior knowledge with users and switching agendas to put off dealing with users' concerns (Williams, 2004) and fail to deal with issues raised by users (Milewa, 1997) maintaining their dominant positions as service gatekeepers.

Despite the involvement of service users 'becoming less discretionary and more compulsory for the providers of services [...]' (Crawford et al., 2002) there is little evidence of involvement having any effect and even less evidence describing if involvement has a positive and sustained effect on organisations and on service delivery (Crawford et al., 2002). Commentators have suggested that different levels of management and professional groups within organisations may construct and value involvement differently (Daykin et al. 2004; Milewa et al. 1997) and service users may be used to validate or legitimise the status quo rather than producing outputs or contributing to changes being made.

While the type of involvement which shapes the development of policy is involvement at board levels the majority of user involvement in the NHS is indirect

(Tritter et al, 2003). Despite there being numerous schemes available for users to be trained and their skills and confidence to be developed to enable involvement, there are often not the positions at a higher level for them to be involved (Tritter and McCallum, 2006) leading to health organisations failing to involve a diverse range of service users and little opportunity for their views and opinions to be captured (Wallcraft, 2003). Although a group of trained users may have the skills to share their knowledge there is the risk of this group of users becoming ‘experts’ or ‘professionals’ and unrepresentative of all users (Tritter and McCallum, 2006). Crawford et al. (2002) explain that involving service users or patients to legitimise decision making is therefore ‘an end in itself’ and not viable to improve the services provided.

Fudge et al. (2008) found similar findings to Crawford et al. (2002), in a study of stroke services in two London boroughs, where the benefits of involving those ‘affected by stroke’ were difficult to identify in terms of changes and the impact involvement had on services and was led by professionals. The findings suggest that those who were involved personally gained (Crawford et al., 2002) more from the involvement in terms of their increased knowledge about the health area and available services, social opportunities, meeting others in similar situations and feeling that they were being listened to by professionals. Rush (2004) recommends that the key to resolving ‘tensions’ between professionals and users is for the two groups to engage in dialogue and be open about the differences they have. However, Fudge et al. (2008) emphasise that because service user involvement can be a costly

process, there is a need for a 'critical debate' and evidence of the purposes of involvement and the benefits it produces in service development.

If users are not provided with information about the opportunities available then involvement may 'become closed exercises designed to legitimise the policies developed by bureaucrats' (Gregory 2007). Differing views on what the outcome of involvement should be, and unequal access to resources and information may lead to an unbalanced opportunity for users to be involved (Church et al., 2002). Users may become alienated during meetings finding themselves unfamiliar with the issues being discussed. Often the language used in management meetings where professionals are present is unfamiliar to users leaving them feeling isolated, unheard and 'like an outsider during discussions' (Oliver et al., 2004: 86). As Anderson et al. (2006) explain meetings can be daunting for users who may be faced with going through an initially unknown and difficult period before they become accustomed to the processes and jargon of meetings.

Fudge et al. (2008) similarly found differences in the concepts of involvement within professional and service user groups for a number of reasons including each individual's needs, beliefs and views and individual situations. Degrees of involvement were largely controlled by professionals and involvement differed in the different areas, from one off consultations and satisfaction surveys in one work stream, to service users having a more active role in the development and delivery of services such as training staff, peer support and information development in others. Ultimately areas where service users could apply their knowledge and expertise were

limited and so user involvement was not seen to change the relationships between patients and professionals.

Organisations not only retain the power to decide how to use consumers' input but also the extent of how much they are involved (Anderson et al., 2006). Professionals also tend to have a range of views of involvement including how users should be involved and what the results of involvement should be where the background of the professional and their career history affects their interpretation of involvement (Fudge et al., 2008). Hopton and Nolan (2003) also identified that there were inconsistencies in the ways users were involved in policy making and service planning, development and delivery in contrast to government plans and intentions. A number of studies have therefore concluded that professionals use involvement as a tool to legitimise their decision making and control the way involvement is enacted (Crawford et al. 2002, Donovan and Coast 1996, Roy and Cain 2001, Rush 2004, Rutter et al. 2004, Wellard et al. 2003, White 2000) restricting any benefits users may contribute to service provision.

### **Social movements, user led organisations and the voluntary sector**

The anti-psychiatry and disability movements as well as other human rights movements served as catalysts for the service users and survivor movements in the 1970s and 1980s. Social movements are made up of a collection of individuals, groups or organisations loosely bound together who share basic ideas and views about a problem and who mobilise themselves to participate in a range of activities

or projects to address them (Crossley, 2002) and are known for their ability to work independently gaining political leverage rather than being controlled by state agendas. Membership in a social movement can be seen as an opportunity to form an identity fulfilling a person's need to identify with a group (Stryker et al., 2000).

Joining a social movement organisation enables a person to assume a role within the group and an identity linked to the group or organisation (Della Porta and Diani, 2006). Prior social ties are seen as important and increase the likelihood of participation by a person in a social movement, where they are able to strengthen their 'activist identity' and the link between their identity and the movement (McAdam and Paulson, 1993). Social movements then are seen to invoke the social identity of its members to prompt action from them and gain legitimacy from its stakeholders (Davis, 2000).

Cotterell and Morris (2012) describe how as involvement becomes embedded in practice and service commissioning; it can become professionalised with experiential knowledge being translated in order to be accepted as an 'involvement contribution'. User movements however remain autonomous in that they are seen to '[...] own their distinct knowledge and to convey this externally' (Cotterell and Morris, 2012: 69) but questions still remain about the benefits and drawbacks of autonomous user led organisations and their work with service providers. Although user groups may not be as radical as social movements, they share similar attributes, in that their collective identity may develop because of their friendships, common goals and shared aspects of personal identities (Stryker et al., 2000), where the collective group identity is influenced by, and influences the personal identities of its members

(White and Fraser, 2000). Self-organisation enables user movements to collectively articulate their views and opinions where they are free from state control and agendas providing them with personal development and empowerment to engender social and political change (Campbell and Oliver, 1996).

The user movement also shares a history of active protest with social movements where user movements are thought to go back as far as 1620 when service users campaigned at the Bethlem hospital in London (Coleman 1996) complaining about their environment and poor food. The 1980s and 1990s saw a rise of user led organisations where service user began to set up their own organisations. Their experiences of being a user were seen as important, rather than their professional knowledge, and constituted their legitimacy to their organisation and membership of the group or movement. As with social movements such as AIDS and environmental groups, user led group too have been faced with criticism from professionals that they are not representative and where the term 'professional user' has been used to undermine the legitimacy of those speaking on behalf of other users or that user groups do not represent 'real users' (Barnes, 2002) .

Alongside policy initiatives, from the early 1990s the government recommended that the voluntary sector work in partnership with the government. The third sector later adopted a central role as contractors in the welfare market but also as key stakeholders in the design, delivery and management of public services (Martin, 2012a: 49). Onwards from this, the third sector were seen as an organisation which represented service users and which possessed 'specialist knowledge and innovative

expertise when dealing with service users, particularly those with complex needs' (Kelly, 2007: 1010). Despite these intentions of government to capitalise on the voluntary sector and its relationships with the public Martin (2012) describes the delivery of services under contract from the state erected new barriers between staff and service users mirroring professional-client relationships of the of the state and private sector (Martin, 2012a: 51).

The voluntary sector including those user groups operating independently of the state exists then in a space where they may drift into 'invited spaces of governance' and risk losing their autonomy and identity or remain in 'parallel discursive arenas' (Barnes et al., 2007) and have little influence on service provision but however retain control over purpose. This is a question posed and explored by Martin (2011, 2012: 52) in his research of the National User Reference Group that Macmillan facilitated. The Reference Group allowed users to talk about service development and occupying a space between a 'parallel discursive arena, where discussions might be limited, and an invited space of governance, where discussions might be constrained'. Macmillan then as a third sector organisation served as a facilitator for the service user voice to exert influence in service provision through combining the experiential knowledge and idea of users and the managerial expertise in gaining influence in the NHS (Martin, 2012a).

In their study (Barnes et al., 2007) of different forms of public participation in housing, health and other fields those groups that retained more independence from the state were able to express their ideas and identities more freely in a 'parallel discursive arena', but nevertheless had less influence on service provision. User

movements and collective action by service users has enabled the production of new forms of knowledge including users' personal knowledge of their experiences. However, knowledge is contested especially that of a group which lacks a professional identity and credibility and thus at times users' knowledge may be marginalised if it does not align with the interests of professionals where it is seen as being too subjective and 'out of date' (Cotterell and Morris, 2012: 65).

Barnes et al. (2007) suggest that when independent user group move into 'invited spaces of governance' they can often lose their autonomy and be controlled by state agendas. Whereas remaining in 'parallel discursive arenas' is easier because groups already share aspects of an identity and are able to share different perspectives on matters of service delivery. This is evident in the women's group and senior citizen's forum in their work (Barnes et al., 2004a) and in other studies where separate organisations are free from state control (cf. Altman 1994 HIV/AIDS suffers; Barnes and Bowl 2001 groups of mental health service users; Epstein 1995, 1996 HIV/AIDS activists).

### **Lay experience or expert knowledge**

There are evident tensions over users' knowledge and its credibility where scientific evidence is often seen as more credible than experiential knowledge leaving users intimidated and marginalised (Oliver et al., 2004). Results from a study examining the participation of parents in community collaboratives for children with serious emotional disturbances reported the different perspectives on 'right' and 'wrong' parents in family involvement, where the 'right' parents possessed certain skills which enabled their involvement (Potter, 2010). Potter's (2010) work highlights that



in order for effective participation to take place, greater clarity and re-framing in policy of how lay involvement should be enacted. This would provide greater clarity to distinguish between the use of consumer paradigms, lay involvement which centres on knowledge and credibility (Epstein, 1996), and consumer models of citizen participation where concerns of communicative democracy and citizen agency dominate (Barnes 1999; Beresford 2001).

Variations between lay and professional ways of knowing have long been documented in medical sociology (Brown 1992; Waitzkin 1989). Lay expertise or knowledge is recognised by policymakers as a public asset (Prior, 2003) but has been questioned in the management and delivery of health services. Prior (2003: 54) suggests that experiential knowledge is of little value in clinical services and so a technocratic rationale for involvement and public participation should not take the place of 'the worthy political aim of ensuring participation and consultation of the lay public in all matters to do with medicine'.

There has been interesting rhetorical issues relating to the use of terms such as, 'lay expertise', 'lay epidemiology', 'lay knowledge' (Martin 2008a; Prior 2003) and as Collins and Evans (2002) outline, what exactly constitutes 'expertise' and how this differs from professional ways of knowing is not exactly clear (Brown 1992; Waitzkin 1989). A number of studies suggest that the risk of disease may fuel the acquisition of distinct scientific knowledge by lay people, where the knowledge possessed is distinct and can make productive contributions to health service development and delivery (Epstein 1995; Lambert and Rose 1996; Nettleton and

Burrows 2003; Whelan 2007; Ziebland 2004). These studies all similarly used patients (Lambert and Rose, 1996) or activities (Epstein, 1995) where the risk of disease fuelled an ability and willingness to become an expert using scientific knowledge and experience therefore enabling legitimacy in providing a valuable input in the management and delivery of health services.

The involvement of 'lay' publics also relied on their willingness and ability to be involved, for example Nettleton and Burrows (2003) describe how patients had to rely on their capabilities to access and interpret the information available on the Internet. In these three cases activists all possessed significant social and cultural capital. Epstein's (1995) AIDS activists mobilised themselves to campaign for their community of patients and were middle class, educated and articulate but it was not their technical expertise which they contributed. Rather, what they contributed was their understanding of human values rather than scientific knowledge and contribution. Legitimacy was therefore in part claimed because of their experiential knowledge of the disease and their scientific knowledge.

A recent study (Thompson et al, 2012) describes how cancer patients deployed legitimising strategies using their experiential knowledge of the disease and scientific knowledge to gain credibility where some users became professionalised in a PPI initiative in a cancer research setting. Patients used their own previously certified professional expertise in cancer research settings while others decided to undertake training courses offered to them as part of their involvement. While participants cited 'experiential expertise' as a justification for their involvement it

was more their possession of prior skills and knowledge, 'professional or certified expertise', that was relevant to the PPI research they were involved in. In addition to their experiential knowledge then, it was their prior education and skills from their previous careers which was vital for their involvement. This leads to what Thompson et al. (2012) note as the 'emergence of the professionalised lay expert' however the explicit processes of how such process 'professionalisation' occurs and the different spaces patients assume are unclear.

This study shares similarities with the work of Epstein (1995) findings on the 'expertification' of HIV/AIDS activities and of Kerr et al. (2007) on 'shifting subject positions' where the term 'hybrid positions' was used to describe how lay participants used both their experiential expertise and their previous certified professional expertise to gain credibility with both professional members and other participants. Kerr et al. (2007) also described how certain participants who demonstrated technical knowledge assumed more prominent roles in discussions and 'carved' out a role for themselves as 'facilitators'.

Potter (2010) describes how 'right' parents were viewed as having 'alternative expertise', situated knowledge and insights into what constituted effective treatments which was valued by professionals and were seen as advocates and mobilisers for others. 'Wrong' parents were seen as too subjective and self-interested, focusing on helping their own children and not on addressing the needs of other children in the community. These parents were also seen as being too mentally unwell to be effectively involved, a view almost always voiced by the professionals and not by

the parents. The parents in this case however represent a different population to that of service users and so hold a different body of knowledge and in turn role in involvement and participatory initiatives. Nevertheless, this study represents a case where those involved, although they were the parents of the children, were involved based on their knowledge and abilities.

Although the acquisition of scientific knowledge by patients provides them with credibility amongst scientists (Epstein, 1995), there are suggestions that those involved also require 'practical knowledge and personal experiences' (Litva et al., 2002) and additional skills (Potter, 2010), rather than simply scientific or experiential knowledge of the illness. Those involved require additional skills where they need to be 'rooted' in their experiences 'but not bound by it' and possess an ability to 'turn their experiential knowledge into something else: a translation process where their knowledge is transformed, in their own mind, and in discussion with others [...], into something generalisable: something that can be acted upon' (Cotterell and Morris, 2012: 68).

The knowledge that service users bring is seen to reflect their title, e.g. patient representative or the usual suspects (Cotterell and Morris, 2012) causing tensions between users where many users feel that patient representatives cannot claim to have knowledge of a number of patients. Experiential knowledge then is also contested and seen as out of date, too subjective and therefore unrepresentative of the wider user community. Cotterell et al. (2011) suggests that other skills including the

knowledge users bring from their working background and general life skills are integrated into involvement activities. However, these forms of experiential knowledge are often unrecognised by the professionals service users work with, experiential knowledge only being valued if users also possess scientific knowledge. This contrasts from Potter's (2010) work where she suggests that 'other skills' are valued by professionals. Cotterell and Morris (2012: 67) describe how there appears to be a paradox in cancer care where although '[...] the involvement of services users, of people affected by cancer, is rooted in policy and also now in practice, there are limits placed on the experiential knowledge that is permissible'.

Service users are now seen to possess certain knowledge and skills valuable to involvement but what these skills and knowledge are exactly remains blurred. Although over ten years ago, Hogg (1999) explained how the concept of 'lay people' and 'expert' needs refining to reflect and give value to the skills and experiences of service users, concepts which to date remain unclear. Existing tensions in healthcare between managers and health professionals and top down policies putting pressure on service provision to involve users are exacerbated when service users are thrown into the mix. Further, different forms of knowledge enable those involved to be seen as credible to professionals but where certain forms of knowledge and expertise remain contested. As Prior (2003) argues lay expertise cannot replace medical knowledge in decision making on the future of medicine however it is unclear are how participants' claims to knowledge and expertise are mobilised to negotiate status to influence decision making (Kerr et al., 2007).

Ives et al. (2012) argue that in order for involvement to be beneficial PPI models must incorporate the inclusion of a lay expert with the relevant experience of illness and service use and who is also representative of the public and able to mitigate exploitation and elitism in research processes involving the public. However, this balance of the 'ideal' public Ives et al. (ibid) explain to be near impossible. Through empowering and training users to enable them to be involved and contribute substantially arises a professionalisation paradox whereby the once 'lay' users lose their experience of the illness and their lay perspectives become 'tamed' and closer to that of a professional researcher. Further, this professional socialisation places certain users in a more privileged position to others following the formal training and education leading to their professionalisation. Certain users may view PPI as work experience (Ives et al., 2012) and over time this may lead to a divide within the user community (Lakeman et al., 2007) on the basis of expert knowledge and skills and the exclusion of certain users by those who perceive themselves as more legitimate, able and 'professional' (El Enany et al., 2013)

Staley (2013) argues that there is no paradox with PPI in research because there are different levels of involvement for different types of activities that require different users. However, these different 'levels' of involvement alone lead to fractures within the user community and a hierarchy based on experience and skills with the same user repeatedly involved by professionals who is more able and easier to involve than others (El Enany et al., 2013). Further, the service user's motivation to be involved is often overlooked, there is the assumption that users are striving for 'the cause' while they may instead view PPI as an opportunity for work experience (Ives

et al., 2012) , ‘a platform for a more or less conscious narcissistic quest’ (Lehoux et al., 2012, p. 1848), identity reconstruction or simply self-satisfaction . The concern with training and skilling service users for PPI, is not that they lose their ‘laity’ but that they become unrepresentative of the user community. That is, rather than retaining their service user identity and being part of the user community, the professional socialisation they undergo draws them closer to the professional community of managers, researchers and health professionals; i.e. they begin to think in the same way, speak the same language and follow the same management routines.

### **Representing the user community?**

State guidance on involvement has varied at times emphasising the need for representativeness while in other documents demonstrating and questioning how those who are involved could be representative:

‘Unrepresentative of who or what? Patients and members of the public bring their own experiences to the debate. Unless they are speaking on behalf of a patient’s group or an established forum they are rarely able to represent the collective views of others.’ (DoH, 2003b: 50).

One of the reasons for abolishing PPI forums was that they were not representative of their communities and the existing system was too bureaucratic and subject to ‘tick the PPI box’ (DoH, 2007a: 28). There were fundamental objectives of patient representatives where it was cited that too much power was given to a few individuals who were members of the forums:

‘I think there is a sense that [PPI members] are representative patients rather than patient representative. In order to do that they would need a good deal more diversity’ (DoH, 2007a: 28).

Nevertheless, the Department of Health emphasised how the public as taxpayers and beneficiaries of healthcare should have a say in service development and priorities (DoH, 2001) where the public and patients should be consulted ‘[...] at the beginning and throughout all stages of a process’ to ‘plan services; develop and consider proposals for changes in the way services are provided; make decisions affecting the operation of services’ (DoH, 2003b: 39). PCTs and trusts were instructed to involve patients and the public for their views about services contributing in a variety of ways using their ‘knowledge, experience of...using services, behaviour, wants, information needs, attitudes, and considered and informed opinions’ (DoH, 2003b: 39). In England, the Department of Health (DoH) requires that health practitioners ensure ‘a representative cross-section of people, community groups and key stakeholders have been involved from an early stage’ (Department of Health, 2003b: xii) in service provision.

Service users are given numerous names including; clients, citizen participants, users, carers, consumers, lay people, survivors, service users and research partners or associates (Buckland et al., 2007) where there is a long standing argument on who represents a service user and how representative they are of the wider user community (Beresford 2005; Crawford et al. 2004). Third sector organisations and promoters of service user involvement stress that organisations should focus on including a diverse range of users rather than simply service user representatives



(Beresford, 2005). User representativeness has been widely cited in studies as a key concern in involvement initiatives highlighting the lack of clarity of a lay person's role (Hogg and Williamson, 2001). Further ambiguity exists over whether a lay member represents his or her own perspective or a particular group (Coulter, 2005) suggesting that they may be unrepresentative of the group or network they are recruited from and therefore may not express the views, attitudes and experiences of those being represented (Hogg, 2007). Questions also arise about who a lay member is representing, are they representing 'users of particular services or simply themselves' and how accountable they are to those who they represent (Pickard and Smith, 2001:173).

As discussed above the different forms of knowledge and experience service users bring to involvement activities differentiates users from one another but also leads to leads to different 'types' of users. Professionals then are seen to involve those users who possess the skills and experience necessary for involvement activities and in most cases because of this are repeatedly involved. Although not empirically supported Lakeman and his colleagues (2007) reflecting on their work from psychiatric services are of the personal opinion that over the years a hierarchy of service users in mental health has emerged. This consists of 'celebrity or corporate service users', 'professional service users', 'members of service users groups and organisation' and at the bottom of the hierarchy those users who consist of the vast majority of mental health users and who are the most legitimate to the title of 'service user' but who have the least authority. Celebrity or corporate users are those who are usually highly articulate and charismatic and who concur with medical and

professional views rather than challenging prevailing practices (Lakeman et al., 2007). They suggest that this creates of a hierarchical structure of knowledge and authority in the service user movement is problematic because those ‘professional’, ‘celebrity’ and ‘corporate’ service users who sit at the top of the hierarchy claim to represent the user community but in reality do not.

These users who sit at the top of the hierarchy are often confident, talented and remarkably charismatic and may over time become ‘corporate entities’ who demand fees for their consulting and who usually concur with medical views rather than seriously challenge existing practices and views. Lakeman et al., (2007) highlight how this stratification we are beginning to observe in the service user community, reflects the profession of psychiatry where knowledge is used to gain authority and the truth is ‘declared rather than discovered’ and where legitimacy is rarely challenged. As we observe in professions such as medicine and law, those dominating the profession seek to maintain the status quo where their presumed expertise provides them with an elevation in the hierarchy of power and status. Unclear are the processes behind this stratification of users which Lakeman et al. (2007) describe and this is where this work seeks to make a contribution by highlighting the processes of stratification in the user community.

The development of close relationships with the ‘usual suspects’ users may help to overcome specific issues such as managers’ and healthcare professionals’ common resistance to making their jargon understood to users (Stickley, 2006), which commonly leaves lay users confused (Rhodes et al., 2002). In essence, the ‘right’ user tends to fit the stereotype of being well educated, well-spoken and well off’ and

often middle class, i.e. possessing the same characteristics as the healthcare professionals selecting them (Church et al. 2002; Crawford et al. 2003). Certain groups of involved users may rely on professionals to make their voices heard and professionals too rely on users for legitimation of their decision (Mort et al. 1996; Newman et al. 2004) demonstrating strategic relationships between users and professionals (Rutter et al., 2004). Through a process of self-selection, the involvement of the 'right' user by health professionals and reliance on the 'the same traditional middle-class cross-section of citizenry to represent the interests of all' (Church et al., 2002: 17) an unrepresentative sample of users are involved who are not only unrepresentative of the user community but fail to represent the views of other users.

Although there is evidence suggesting that professionals are moving towards supporting user involvement, the enactment of user involvement in practice is often more complex than envisioned in policy. Certain users may self-select themselves for involvement (Church et al., 2002) and professionals may play the 'user card' (Harrison and Mort 1998; Mort et al. 1996) as a means of legitimising their own interests (Contandriopoulos et al. 2004; Harrison and Mort 1998; Rowe and Shepherd 2002), and use their positional power as 'gatekeepers'. In so doing, they seek to remain in control and defending existing power relationships (Barnes 1999; Contandriopoulos 2004; Martin 2008b), with service users struggling to assert any authority over professionals delivering healthcare (Hodge, 2005).

Linked to this, professionals may be selective in their uptake of users' views; i.e. one who is articulate and educated (Learmonth et al. 2009; Martin 2008a, 2008b) and will commonly employ a service user who represents a 'safe pair of hands' (Hogg, 1999: 100), Thus, health professionals may marginalise or gloss over those users' contributions that do not serve their interests (Campbell 2001; Hodge 2005) and conflict with their ideas of competence and legitimacy (Milewa 1997; Williams 2004), claiming these users' knowledge is too subjective (Hogg, 1999) and often constructing users as lay patients rather than knowledgeable partners (Martin and Finn, 2011). Consequently, some user groups are unrepresented, particularly those more socially excluded from society who may be hard to reach out to or those with a significant mental health problem (Boardman et al., 2010).

Rather than involving the masses, Prior et al. (1995) advocate experiential representation as an alternative. Representation, then, is based, '...shared experiences where needs are actively and subjectively assessed, enhances the legitimacy of representation when economy of time and problems of scale restrict participation by all' (Frankish et al., 2002: 1476). Involvement then becomes a question of common experience in the situation where a group is being represented and so offers a more legitimate alternative to demographic, electoral or statistical representations of commonality. In performing the role of citizen or a public representative, those who are involved use their 'practical knowledge and personal experiences' (Litva et al., 2002: 1834) of health settings.

A paradox arises therefore where the longer a user is involved the more familiar and experienced they become but in the same instance it is these 'usual suspects' who are difficult to replace with new users who are able to understand the context of the initiatives they are involved in (Greenhalgh, 2011). Hogg (1999: 100) explains that healthcare professionals will commonly employ a user representative with 'lay' experiences, but one already known to the organisation who represents a 'safe pair of hands'. Service users repeatedly involved in service development come to represent close allies of healthcare professionals, and over time become co-opted and sympathetic to professionals, rather than public or other users' interests (Hogg 1999).

Using those service users, who are known to the organisation has advantages in that their identification, 'recruitment' and training are already complete, and professionals feel comfortable working with them (Hogg, 1999). While professionals find this convenient, others propose that in order to be representative, existing service users should refer back to a reference or interest group to engage others and avoid a situation where the same users are repeatedly involved in service development (Hogg, 1999). Meanwhile, service users argue that others, such as those professionals commissioning or delivering healthcare, are not expected to be representative and therefore question why users have to be representative (Hogg, 1999). A tension exists then, 'in that lay participants must move between representing the broader community and also acting for, or protecting the interests of vulnerable groups (e.g., the poor, handicapped, persons with mental illness) in society' (Frankish et al., 2002: 1476).

While those involved are a small representative group who enable professionals to justify their decisions, these users may also personally benefit from the experience of involvement (Fudge et al., 2008) which may be seen to widen the gap between the user community and those involved users. Rose et al. (2010: 399) found that activists often feel that professionals view them as unrepresentative, an excuse users felt was used to 'invalidate their views or exclude them from involvement activities' because they were more critical than non-activists or the general wider population of users. Professionals may want to hear the 'authentic voice' of experience but not if it is expressed too negatively' (Rose et al., 2010: 390) or involve users simply as a means of legitimising the decisions made by policy makers (White, 2000).

Professionals may argue that it is not possible to involve everyone and so select a chosen few, or they may seek to undermine the legitimacy of users by claiming they are unrepresentative if they make suggestions which are different to professionals. Representativeness becomes a key concern for user involvement where only certain users are able to understand certain work and so involvement may simply become a 'complex justificatory negotiation' (Martin, 2008b) between the different groups involved. Thus as Martin (2008a) suggests there is a 'thin line' between democratically involving a representative group of the public and involving certain subgroups or 'experts' of the public. Hogg and Williamson (2001) suggest that it is assumed that lay users will bring 'ordinariness' to a group, but in reality found that lay people tended to have dominant interests, i.e. those aligned with health professionals and doctors and may come from similar backgrounds to those of professionals; challenging interests, that is, those aligning with executive or

managerial perspectives or those who support patients' interests. There is therefore no guarantee that service users will work and speak for the user community especially if they have been coerced or encouraged to be involved by health professionals (Greenhalgh, 2011).

In various national (Macdonald 2003; Contandriopoulos 2004; Gollust et al. 2005) and international contexts (Church et al., 2002) patient or service user representatives have been noted as often being from different backgrounds to 'ordinary' patients and are more likely to be white, educated and middle class. In some cases, service users may be volunteers where their work is unpaid, or may be peer support workers or specialists (Fadden et al., 2005) who may be paid. In their study of service user 'consultants', D'Sa and Rigby (2011) show how some service user consultants were seen as valuable in bridging relations between service users and staff members, but their role was still not accepted by all professionals, with lack of clarity around how service user consultants assumed their role and who provided them with the role of 'consultant'.

Lehoux et al. (2012a; 2012b) argue that understandings around who should be involved and who a citizen is suffer from 'lightness' and the pursuit of the 'ordinary' citizen is misleading. As a result the richness and complexity of those involved is overlooked. While policy guidance calls for the involvement of 'everyone' (Branfield and Beresford, 2010), Martin (2012b) argues that a policy context calling for public participation to 'permeate everything' may do a disservice to areas where legitimate contributions can be made because the participation of everyone approach

can often cause tensions in practice. As Martin (2012b) suggests not only is the purpose and 'who' is involved important to consider but also the processes by which those involved are selected.

Lehoux et al's (2012a) work describes those involved in a Canadian science/policy genetics network (GeNet project) where publics viewed as too 'interested' were formally excluded including activists, patients and their relatives. The idea was to engage those who were 'disinterested' but who were articulate and experienced in public activities rather than the 'ordinary' public who may have had a vested interest in the activity. While the study contextualises 'who' involved citizens are, it highlights the narrow selection of those involved. Although those involved were 'disinterested' publics they all possessed a certain degree of cultural, relation and cognitive resources; i.e. they were all able to mobilise themselves, were educated and professionally trained in different fields.

Lehoux et al. (ibid) point to the complexity and 'richness' of those involved in GNet, and indeed they were rich in terms of the knowledge, skills and personal backgrounds they brought to the networks. All however were relatively socio-economically advantaged in relation to disadvantaged groups such as the poor, homeless and elderly. The study demonstrates that in the quest for a disinterested public, those involved were unrepresentative of the wider public in terms of their backgrounds; what of those publics who are not educated and socio-economically advantaged? The alternative seems to be to train and educate those involved at the risk of them losing their 'laity' (Ives et al., 2012) or the pursuit of an 'ordinary'



public (Martin, 2008a) who does not hold specialised expertise and knowledge and conflicts with the expectations managers and health professionals have of involved publics (Learmonth et al., 2009).

### **Representative of whom?**

Discussions on representativeness and the inclusion, or exclusion, of certain publics are located in other fields, notably in political theory and the critical field of post-colonial theory. In political theory, notions of representative democracy or deliberative democracy have long existed to justify decisions made by those representing the public to advance both 'individual and collective understanding' in democratic forums (Gutmann and Thompson 2004, p. 12). Deliberation, then, is this seen to provide an opportunity for participants to learn from one another and develop new views and policies through the expansion of their knowledge and the sharing of ideas (Gutmann and Thompson 2004). This lead to better understandings and public decision making and more participative 'ordinary' (Fung and Wright 2001) describe empowered deliberative democracy where the empowered 'ordinary' citizen is involved in reforms addressing regulatory agencies and restructuring democratic decision making across different countries) and politically sophisticated (Gastil and Dillard, 1999) citizens.

However, deliberative democracy cannot include the masses and therefore questions of representativeness and who represents the public and decisions being made become central. Deliberative democracy can be seen to be tied in to identity group politics and therefore also connected to service user involvement especially to

mental health illness which has an associated historic and political history. Democratic politics is bound up with how people and groups identity themselves, their interests and what they therefore want especially so if they are politically relevant (Gutmann 2003, p. 15). This is evident in social movements and service user groups that work to improve services and equality in health settings by involving the voice of the user, a voice historically seen to have little legitimacy amongst health professionals. However, since public involvement is now enshrined in policy in England, the once marginalised voice, can now be seen to be taken more seriously by health professionals and although arguably it is often still side-lined and used tokenistically, nevertheless the once 'outsider' is seen as crucial to health service development and improvement.

Similar to policy initiatives on public involvement in healthcare, deliberative democrats also believe that the public should not only be involved in actual decision making. However, these processes are often difficult tasks that need to overcome political, institutional and social obstacles. To overcome these, deliberative initiatives may be advertised to the public so that allowing those who are interested to self-select or those organising such initiatives may actively and directly recruit interested publics through some form of representative sampling process (Ryfe, 2002). Although self-selection is easier for organisations where pre-existing networks may exist, it also attracts 'homogenous groups' (Ryfe, 2005) that are associated with higher education levels linked to certain social classes and races. Ryfe (2005) explains that those who are self-selected are most likely be educated, white and middle class, a fundamental principle that goes against deliberative

democracy where all people should in fact be engaged and given the opportunity to participate.

Further, in more senior positions such on executive committees and at management level, patient and public representatives are more likely to be socio-economically (linked to education and income) unrepresentative thus limiting the representative voice given to the wider public and patient community (Wright, 2013). Wright (ibid) identified how patient trustees served in different capacities and higher class non-representativeness patients were more likely than lower class representative patients to serve on executive committees. The concern here is that the voices of disadvantaged and unrepresented groups are excluded and privileged ones are over represented.

To overcome the chances of the inclusion of a homogeneous group of publics, random selection may serve as an alternative that provides an equal opportunity for a diverse group to be involved. Although the group may be from a wider representation of the public, those involved may be unable represent a group or community and therefore would be unrepresentative (Ryfe, 2005). Added to this, during their participation they are expected to undergo learning such as during lay participation in the judicial system (Abramson, 1994) which distances them from the 'ordinary' representative public. Further, privileged groups (such as the white, wealthy and male) may need to be actively excluded and their voices 'muted' (Dovi, 2009) from being involved to avoid the under representation of marginalised voices and historically disadvantaged groups (Wright 2013; Young 2000).

Parkinson (2003) suggests that statistical and electoral models in deliberative democracy may be used, involving random selection, to overcome involving those who are self-select or who are selected based on their characteristics or skills. Representative or deliberative democracy can therefore be seen as being bound up to accounts of legitimacy (Parkinson, 2003) where outcomes are legitimate to the extent they receive reflective assent through participation in authentic deliberation by all those subject to the decision in question' (Dryzek, 2001, p. 651).

Saward (2006:301) suggests that direct democracy in political representation is more complex than suggested. He explains that the represented should choose their representatives and representatives should 'choose their constituents' portraying them adequately based on the characteristics they possess. Although 'creative actors' may act as 'agents' on behalf of others, Saward (2006:302) emphasises that 'no would-be representative can fully achieve 'representation', or be fully representative' and by no means can their claims be 'authentic' or 'true' of members of a community or society they are representing.

Challenges surrounding representativeness and deliberative democracy can be seen to be exacerbated in long term health conditions such as mental health where self-selection and random selection is affected by the condition of the public or service user or the associated stigma. Discussions around the issues concerning the representation of certain social groups and the dynamics of representation is long standing point of discussion in post-colonial theory and political theory, where often indigenous groups and women are excluded from society's political representation (Spivak 1988; Saward 2000, 2006).

Spivak (1988), a postcolonial intellectual, is concerned with revealing the silenced and disempowered voices. She focuses on historical experiences of the subaltern woman linked to the times of colonial insurgencies in India and the repressed voice from discourses in historical and political representation. In her notable work, 'Can the Subaltern Speak?' (1988), she emphasises that the voice of the woman, the worker and other marginalised religious groups are often represented by an elected representative speaking on their behalf. These representatives represent disempowered and marginalised groups, speaking for them as a collective and unified voice in political discourses.

For Spivak (1988) however, this unified political identity is an effect of the dominant voices that represent these disempowered groups rather than a true representation of the true woman, or indeed subaltern whose voice is often not recognised or heard within powerful political systems of representation. Spivak's work chimes with notions of public involvement in health, and specifically mental health, where those with mental health illness are often stigmatised, excluded and lacking legitimacy and knowledge to be involved alongside health professionals and managers in bureaucratic and politicised health systems.

In discussions around deliberative democracy, Fox and Miller (1997) describe how involved publics must make useful contributions; 'No free riders or fools allowed' (McSwite, 1997: 178). Campbell (2005) too describes how professionals in public administration disqualify knowledge which does not fit into models of citizen engagement and where the 'good citizen' is envisioned in participatory activities.

These citizens Campbell describes are 'quick learners', who are able to work smoothly with professionals, are like minded, and are able to articulate their experiences in a calm and rational manner. In her work on citizen engagement, Campbell describes that involving these 'good citizens' may not seem initially problematic but, '[o]ver time, a static pool of citizen participants tends to lose touch with the values of the average citizen' (Glaser and Bryan, 2003: 28).

Similarly, those who act as representatives will be required to speak for others without reference to them and as a result be open to transformation of their views and possibly their identity (Abelson et al., 2003). Those users who want to be involved for 'the cause' form relationships with others during the involvement process resulting in 'spaces in which collective identities not articulated previously might be constructed' (Barnes et al., 2004a) with involvement therefore being seen as a process where identities and discourses are shaped. In addition to those involved collectively striving for change, there are suggestions that those involved may distance themselves from the wider public where '[...] notions of representation may become rather amorphous and fluid after the initial process of group formation' (Barnes et al., 2003: 396). We observe then that those involved are subject to transformation such as to their identity and become 'confident' (Beresford and Campbell, 1994: 317) through the involvement process and can be seen to become unrepresentative in some way.

While Campbell (2005) and others have addressed studies on civic engagement, participatory processes and deliberative democracy namely in the United States (Potter 2010), links to user involvement initiatives in England are evident. Primarily,

issues of engaging the 'good citizen' (Campbell, 2005) is one which resounds with current themes evident in extant literature of user involvement and involving the 'right' users who is a 'safe pair of hands' (Hogg 1999,: 100). Is the motivation of those wanting to be involved and putting forward the input of the public the 'conscious and thought-out desire to be, or to become, a certain type of person' (Campbell, 2005: 689), are service users altruistic or is there an element of self-interest to assume a more superior role as Lakeman et al. (2007) suggest.

A number of studies examining different forms of civic involvement and engagement have identified that those involved such as in political activism (Teske, 1997) develop certain identities for themselves and are transformed through these processes. In any case, these processes of user involvement, civic engagement and deliberate discourse are all subject to some element of identity transformation, the question however, is if as a result of such processes certain publics are more listened to and involved than others where certain users are at risk of being marginalised and involvement eventually becoming unrepresentative.

If 'participants have to be able to communicate insights and concerns in such a way that others understand what the issues and options are, and where the constraints lie' (Brownlea, 1987: 606) then only certain users can be involved who are able to understand certain issues and the criteria for inclusion a legitimate one (Daykin et al., 2004). As Barnes et al. (2004b) describe there is a 'politics of presence' where a range of representativeness is present in different situations and "how 'old' institutional norms [interact] with 'new' norms of deliberation and involvement". The involved public, then, is more than a representative of their community because

they must possess the skills and qualities required for involvement which their legitimacy depends upon.

In this sense, the patients and activists who do participate and are involved may be unrepresentative of the population because their abilities such as their literacy, cultural and social capital are not representative of all users. Thus we arrive at a point where representativeness that might be sought through random selection or electoral processes is to a degree counterproductive because users may not possess the necessary knowledge required for involvement. Inevitably then, there exists a paradox between involving those who possess these criteria and the exclusion of those who lack these reflexive skills (Campbell, 2005).

### **Summary**

This chapter has considered the history of involvement where competing democratic and technocratic rationales for involvement exist and where policy pressures are calling for the increased involvement of the public across all levels of health provision. Evident however are the disjoints between policy and practice where calls from policy dictate a representative involvement of the public but fail to detail how and where to involve users and who exactly service users are. If service providers are to involve service users to gain their experiential knowledge of the disease or illness then which service user is a legitimate source for involvement and why and what knowledge is seen as credible to professionals is a challenging exercise. With different opinions on what constitutes lay expertise and competing paradigms of



experiential knowledge and acquired scientific knowledge lay publics possess, how do certain users acquire the knowledge they bring to involvement and what are the implications of this in the user community?

A number of empirical questions then arise. If transformation through the involvement process occurs in some way then issues of representativeness and representation and links to democratic and technocratic rationales for involvement need to be considered. Who is the 'right' user that is more attractive to professionals? Is representative involvement possible in long term conditions such as mental health and stroke where service users may not be physically or mentally well enough to be involved and If lay users become experts over time, how does this happen and whose interests are being served? What knowledge makes users 'expert'? There are suggestions that some users or activists acquire varying amounts of knowledge leading to different 'types' of users but it is unclear how and why this happens. If transformation occurs through the involvement process, do identities of users change through acquiring knowledge and being involved with professionals? In being involved do users retain their identity as patients or do they adopt different roles and why? Finally, does the acquisition of knowledge provide users with leverage and over whom? These questions are explored in the empirical chapters.

By examining the micro processes of the involvement process, who users are, how users are chosen for involvement processes, and what knowledge they contribute to involvement, I aim to highlight why professionals involve certain users and what knowledge users possess makes them attractive for involvement. However, it is also

their expert knowledge gained through the involvement process that leads to a hierarchy of users. In the same way as professions claim jurisdiction using expert knowledge, certain users self-select themselves for involvement. Using their expert knowledge to claim professional status they cast other 'less expert' users as amateurs unable to be effectively involved alongside professionals.

**CHAPTER 3: PROFESSIONS AND HEALTHCARE:**  
**PROFESSIONALISM, PROFESSIONAL PROJECTS AND**  
**EXPERT KNOWLEDGE**

**Introduction**

Following on from the previous chapter on service user involvement this chapter draws on the sociology of professions literature to describing how professions delineate jurisdiction and draw upon their knowledge to claim status and power and in doing so develop a distinctive identity that enhances exclusivity and privilege (Currie et al. 2009; Currie et al. 2010; Fournier 2001). Linked to the previous chapter and issues of representativeness, the different roles users adopt and discusses around lay knowledge, this literature is drawn up to highlight in the forthcoming chapters how service users in the same way as professions, claim professional status by carving out an expert body of knowledge to delineate jurisdiction.

Structural changes and reforms across the health service have seen the growing managerialisation of public services where doctors are becoming managerialised to fend off encroachment by managers (Waring and Currie, 2009). Managers however are also competing with the medical profession for control and territory and are professionalising themselves through professionalisation strategies including educational programs and professional memberships (Noordegraaf and Van der Meulen, 2008). The integration of service users and the publics into a management driven and professional environment, where both managers and health professionals

are tasked with involving users has created a range of struggles for users including representational issues, power struggles and competing claims for legitimacy leaving involvement subject to becoming a 'tick box' exercise (Beresford and Campbell 1994; Hodge 2005). As a response to these struggles we observe the selection by professionals of the 'right' user for involvement activities and the self-selection of those wanting to be involved leading to unrepresentative involvement.

Added to this, Lakeman et al. (2007) suggest a hierarchy of service users is has emerged akin to the profession of psychiatry where certain users are claiming authority. The aim of reviewing this literature is to later draw out in the comparisons between how service users in the same way as professions make claims to expert knowledge thereby stratifying themselves from other users in a quest to gain professional status leading to unrepresentative involvement. By examining the processes of how professions delineate jurisdiction using expert knowledge and claim professional identity, and the interaction of the medical profession and the public, this chapter serves to inform service user involvement studies highlighting the processes of stratification in the user community.

This chapter runs as follows. First the literature on professions is reviewed including Second, work on professionalism and professionalisation is discussed. Third, work on professional projects is explained, describing how professions close off their markets and gain control using expert knowledge. Fourth, professions and notions of expert knowledge and control are reviewed. Fifth, professions in healthcare is

discussed, the interaction with service users and the implications of this before the chapter concludes with a summary.

### **Defining professions**

The relationship and changing nature between professionals and professions have been widely studied (Abbott 1988; Broadbent et al. 1997; Freidson 1994; Macdonald 1995; Malin 2000). The public sector has attracted much interest as it continues to undergo radical reforms and changes (Ackroyd 1996; Reed 1996), particularly the medical profession which has been noted as an almost prototypical profession (Fitzgerald and Ferlie 2000; Harrison and Pollitt 1994) where professions have been impacted by changes in the public sector (Forbes et al., 2004). These studies have moved away from early functionalist and trait theories which discuss what a profession is and the basis of professional status and privilege (Freidson, 1994) to examining how professions use professionalism as tools to gain, maintain and legitimise control over professional work and other groups (Freidson 1994; Larson 1977) to gain privilege economic rewards and social status (Macdonald, 1998).

A number of studies have avoided defining what a profession is and instead offered insights into the contradictions and wider sociological debates about professions (Evetts, 2003b; 2012; 2013) without explanations of how occupations became labelled as 'professions' (Harrison and McDonald, 2008). Rather than defining a profession, Evetts (2003b:397) approaches professions as a generic group of occupations based on knowledge both technical and tacit and a 'distinct and generic

category of occupational work' (Evetts 2013:4). Freidson (1970: xvii) defines a profession as, 'An occupation which has assumed a dominant position in a division of labour, so that it gains control over the determination of the substance of its own work. Unlike most occupations it is autonomous and self-directing'.

Parsons (1954: 78-79) viewed professions as a cluster of occupational roles with valued functions in society and conceptualises them in terms of their 'functionally specialised fields'. Professional power and authority exerted by professions was part of their functional speciality and Parsons (1954) believed that certain people in society were able to operate in such a way. Professions are conceptualised in a range of ways depending on their professional associations and institutions, daily practices and processes of carving out jurisdictions based on expert knowledge, market closure and professional identity. These conceptualisations and the relationships between professions, professionals and society continue to be central to sociological work (Abbott 1988; Freidson 1994; Macdonald 1995; Malin 2000).

Professions began to be seen more critically in the 1970s where they were seen to operate in capitalist societies as agents of social control (Johnson 1972; Navarro 1976; Zola 1972). The classical example used in the critique of professions was the medical profession (Freidson, 1970) with concepts of professional self-interest, dominance and monopoly to describe the dynamics of professionalism. There has been much debate about the nature of a profession (Freidson, 1988) where professions are seen to have special status both in society and in the division of labour. Professions may engage in jurisdictional disputes and inter-professional

conflict especially during times of organisational change and uncertainty when occupational security and power is not guaranteed (Abbott, 1988).

Larson (1977) viewed professions as an interest group related to capitalist society's class system. This certain group of occupations were seen to engage in a 'collective mobility project' to advance their economic and social position in society gaining a monopoly in the marketplace where they pursue prestige and profit for their profession.

Professions then are in one regard or another knowledge based occupations with professional groups forming strong political alliances, often regarded as elites (Evetts, 2003b) and primarily middle-class occupations (Goldthorpe, 1982). Historic professions such as law and medicine were seen as having an important societal role and defined as social agents who held a monopoly of knowledge enabling them to define their position in society (Parsons, 1951). Power and market monopoly saw professions constructing and maintaining 'market shelters' (Freidson 1982, 1986) where their qualifications and social backgrounds granted them privileged positions in an occupational and ultimately in wider society. In carving out these positions a certain group of individuals were able to enforce collective power on those who did not possess the same knowledge and skills.

### ***Professions and professionalism***

Of increasing interest are the characteristics, norms and values of professionalism that underpins professions. Evetts (2003a:22) describes a 'discourse' of

professionalism where a set of 'persuasive ideas' are interlinked with power and occupational and social change. Although historically professions were typically seen as those practicing law and medicine, Evetts (2003b) suggests it is more important to consider the appeal of the concepts of 'professionalism'. Professionalism can be seen as an occupational value (Freidson, 2001), as a discourse (Fournier, 1999) or a set of values and identities (Aldridge and Evetts, 2003). Freidson (2001:12) used the word professionalism to refer to 'the institutional circumstances in which the members of occupations rather than consumers or managers control work [...] when an organised occupation gains the power to determine who is qualified to perform a defined set of tasks, to prevent all others from performing that work, and to control the criteria by which to evaluate performance'.

As well as the different ideas around what constitutes a profession, notions of what professionalism is are also somewhat amorphous (Fox 1992; Swick 2000). Evetts (2011) highlights that it is the characteristics of the prototypical professions that are of interest because we are increasingly seeing other occupations including social workers, the police and librarians claiming to be professions and demonstrating professionalism in their occupational work (Evetts, 2003b:399). Professionalism means different things in different contexts and across a range of occupations including teaching and journalism that are viewed as 'new professions' (Aldridge and Evetts 2003; Evans 2008). In part, this is due to the changing nature of and widening range of occupations that come under the banner of a 'profession'. For example, in 1999, the Accreditation Council for Graduate Medical Education



(ACGME) in the United States listed professionalism as one of the six competencies for doctors. As part of a raft of requirements that came under the banner of professionalism, resident doctors had to demonstrate professional responsibility, ethical principles and sensitivity to patients.

Fox (1992:4) suggests that the fixation with the term professionalism, including Larson's (1997) association of the word to professions, 'misplaces or excessively delimits the meanings of the term'. Fox (1992) does however describe how notions of professionalism are inextricably linked to a number of important factors including, forms of specialized knowledge, education, financial rewards and even the class system such as the 'petite bourgeoisie'. Professionalism then, is not only the possession of a skill set in a given occupation or a body of specialised knowledge but is also linked to speech, dress, altruism, mannerisms, the ability to deal with complexity and uncertainty, and standards including creativity, honesty and due diligence (Swick, 2000). For example, doctors are trusted to have patient's best interests in mind and administer the best treatment and are able to do so because they possess a body of knowledge that is specialised, accredited and regulated by professional bodies including the state.

In public administration, professionalism should be about ethics, achievement and serving public interest and not about exercising class power, elitism or the exclusion of the 'non-cognoscente' (Fox, 1992), different to Larson (1997), Macdonald (1995) and others who describe how professions carve out jurisdiction using their expert knowledge casting others as ineligible and amateurs. For these writers, professions

use professionalism as part of a value system operating on a societal state or market level (macro), within organisations and institutions (meso), and at a group or actor level (micro) (Evetts, 2003b). Professionalism as a discourse is not used solely amongst managers, but is also expressed in the work of actors, artists and musicians (Evetts, 2005). Once defined as a 'professional' these groups, and others, are able to determine and impose legitimate limits on their work and time, even if being a 'professional' is self-defined (Evetts, 2005; 2012).

Evetts's work on professionalism (for example; 2003a, 2003b, 2005, 2006, 2011, 2012, 2013) emphasises the need to move away from conventional, and arguably out of date, thinking on professions as elite occupations controlling markets in pursuit of status. She suggests that knowledge based work is expanding and the definitions surrounding what an occupational group is are becoming more blurred and less distinct. Evetts (2005) describes two different form of professionalism in knowledge based work; occupational and organisational professionalism. Organisational professionalism is characterised by a discourse of that is used by managers to control work and procedures in organisations and which is regulated by external forms of authority. In contrast Evetts (ibid) describes occupational professionalism, as an ideal type, as a discourse constructed within a professional occupational group. This type of professionalism is based on autonomy, systems of education and training and the formation of occupational identities.

For Freidson (2001) professionalism is related to control where certain occupations gain power through their qualifications and specialised forms of knowledge thus

controlling markets and preventing others access to their work. Professionalism is used as part of a tactical project which includes the mobilisation and development of strategic alliances with established power structures (Larson 1977; Macdonald 1995). As well as the appeal of professionalism being one of status and prestige, it may also act as a system of normative values and mechanism for disciplinary control. The restriction and reconstitution of employees as professionals involves a process of relabeling and ‘also involves the delineation of ‘appropriate’ work identities’ and potentially allows for control at a distance by inscribing the disciplinary logic of professionalism within the person of the employee so labelled’ (Fournier, 1999: 281).

Professionalism then is a ‘disciplinary process’ (Fournier, 1999) acting as a mechanism for occupational groups to establish their responsibility and accountability to the state, clients and other actors with criteria that are valued and needed by these social actors thus gaining legitimacy (Fournier, 2001). (Fournier, 1999) considers professionalism as ‘a disciplinary logic which inscribes “autonomous” professional practice within a network of accountability and governs professional conduct at a distance’ (p. 280), a point relevant and linked to managerial professionalism (Evetts, 2005). Freidson (1988) however uses medicine to be representative of all professions without considering other professions or the potential changes professions may undergo (Evetts 2003a; Swick 2000). Work on professions that dominated in the 1970s and 1980s, centred on law and medicine and focused extensively on ideas of market closure, control and monopoly and the advancement of an elite occupational group, concepts Evetts (2003a) explains need

readdressing and rebalancing since professionalism has different meanings in different occupational contexts.

In healthcare and specifically medicine, professionalism used as a tool to control and exert authority, is changing and with it different forms of expert knowledge and the role patients play in their own care. Instead the ethical and caring dimension of professionalism and the accountability health professionals have in delivering patient care is taking precedent and is emphasised in health reforms and policies. The balance between the doctor-patient and professional-amateur relationship is slowly moving to one that is more patient centred where 'lay' patients are seen to possess certain forms of knowledge necessary to service development and improvement, and which is promoted by policies calling for public involvement.

### ***Professionalisation and professional projects***

There has been a shift in studies on professions from trying to establish who and what professions and professionals are to examining what professions do and how this leads to an exclusive and privileged status in society (Macdonald, 1995); i.e. the processes of professionalisation. Discussions on professions and professionalism began to move on to notions of 'market closure' (Freidson 1970; Johnson 1972) based on the Weberian view of how groups restrict access to groups in pursuit of rewards and privileges to maintain professional status and achieve 'occupational closure' through engaging in a 'professional project' (Larson, 1977). Through this process professions carve out and maintain jurisdiction using expert knowledge and establishing legitimacy in the market (Abbott, 1988).

These processes enable the attainment and maintenance of a monopoly, the encroachment of jurisdiction by others and the upward social mobility of the group (Larson, 1997). In doing so however, it reinforces and exacerbates social injustices and prejudices, such as in their pursuit to exclude those they seen as 'ineligible' where they '...may well exclude those of a particular race, gender or religion and thus play a part in the structured inequality of society' (Macdonald, 1995, p. 29). Groups who share similar beliefs or interests act in a way to circumscribe their membership and defend their resources. In doing so, they will seek to become a 'legally privileged group' and aim for a closed monopoly where 'its purpose is always the closure of social and economic opportunities to outsiders' (Weber 1978:342).

Larson (1990) views professionalisation as a deliberate strategic process by which certain specialist service providers seek to control a market with their expertise therefore obstructing free movement of labour and increasing social inequality. Her conceptualisation of the professional project draws on Weber's (1978) view of social stratification where specialist knowledge constitutes an opportunity for income. In doing so, professions secure a privileged economic and social position by translating 'one order of scarce resources – special knowledge and skills – into another – social and economic rewards' (Larson, 1997) as a process of market closure and monopoly of work (Larson, 1997) and occupational dominance (Larkin, 1983).

Market control requires that there should be a body of abstract knowledge that can be practically applied and a market potential for the knowledge. This is made possible

by broader social structures which shape the social need for a given service, providing professions with the opportunity to gain status and respectability in society (Larson, 1977). Evetts (2011; 2012) uses McClelland's (1990) categorisation of professionalisation (i.e. 'from within' where the occupational group successfully manipulates the market and 'from above' where there is domination of forces external to the occupational group) to highlight how an occupation is able to use professionalism to construct an identity.

The outcome of a successful professional project is a 'monopoly of competence legitimised by officially sanctioned 'expertise', and a monopoly of credibility with the public (Larson, 1977) that 'positions which rank high in expertise generally attempt to maintain or enhance their scarcity, and thus their reward-power by various institutional means...' (Parkin (1971:212). Leaders of the professional project will outline the areas that are not 'amenable to standardization; they will define the place of unique individual genius and the criteria of talent that cannot be taught' (Larson, 1997: 41).

Exclusivity is essential to the professional project but not solely exclusivity of the knowledge base, but also exclusivity to prevent other occupations and established professions from encroaching on parts of the market and to prevent 'ineligibles' from membership. Linked to occupational closure is professional identity. We observe how the label of 'professional' is a sought after identity, enhancing exclusivity and status (Currie et al., 2009). A distinctive professional identity is developed through

career paths, training and accreditation, and socialisation among a group of peers carrying out the same tasks over a period of time (Halford and Leonard, 1999).

Drawing on theories of identity construction, Currie et al. (2010) describe how at times the enactment of policy driven roles, specifically in healthcare, cannot be fully achieved because of pre-existing tensions within occupational groups coupled with rigid institutional structures. Professional identity is relational and open to contest thus legitimacy and status have to be achieved, constructed and then reproduced in relation to other professions and individuals (Currie et al., 2009). As part of professional identity, professions seek to construct the figure of the 'quack' or amateur (Currie et al., 2009) who is unable to carry out specialist work and has to be replaced by 'professionals' (Fournier, 2001).

Dependent upon the construction of a professional identity and the delineation of a body of knowledge, professions require other relevant social actors to accept the legitimacy of the position of the expert professional in relation to the amateur. In his analysis of professionalism Taylor (1995) suggests that the professional produces the 'amateur' which serves to legitimise professional identity. Since, the amateur here is not a self-defined position; professionalism and professional legitimacy rely on the construction of the amateur where the process of professionalism requires the 'invention of amateurism' (Taylor, 1995).

Professions are able to provide a service using their knowledge leading to monopoly control and the marginalisation of those who are unable to challenge them. Halliday

describes knowledge as 'a core generating trait' of professionalism that must become central to the profession with maintenance of exclusive rights over it. Possessors of this knowledge can then form themselves into a group and standardise and control the knowledge and its dissemination dominating the knowledge based services. When they secure market dominance they will be in a position to enter into a regulative bargain (Cooper et al., 1998) with the state, assuming state recognition and regulation for the group, or those who demand the knowledge and social prestige can be gained.

This contested process, rooted in social and historical negotiations between actors, gives rise to professionalisation projects and the maintenance of professional jurisdiction involving processes of social exclusion which can restrict 'access to rewards and opportunities to a limited circles of eligibles' (Parkin, 1974). This process inevitably excludes less privileged individuals or those who are perceived as incompetent and outsiders by those engaging in their own professionalisation project. These exclusionary measures continue to reinforce everyday practices of powerful actors in institutions often dominated by male, white, middle class individuals (Davies 1996; Witz 1992). The ideology of professionalism that is appealing to different groups include not only the associated power but also the exclusive ownership over an area of knowledge; with this come the ability and power to own a problem and control and have access to solutions pertaining to knowledge based problems. (Evetts, 2013)



## **Professions and knowledge**

Specialised or expert knowledge enables professions to delineate jurisdiction and is the basis for autonomy, political and technical control, and professional identity enabling professions to differentiate themselves from competing occupational groups (Abbott 1988; 1995). Through professional accreditation (Daniels and Johansen, 1985), formal training and control over the professional labour market and education (Macdonald 1995) professions seek to maintain their jurisdictions and remain as powerful social actors. These strategies embody the pool of knowledge and power from which professions draw their legitimacy (Freidson, 1994) and which shapes the actions, values and identity of professionals.

Professional actors at the micro institution level can therefore function as 'institutional agents' (Scott, 2008) through defining and applying institutional elements and controlling social spaces by employing authoritative, normative and cultural-cognitive strategies (Finn, 2008). Monopoly, expert authority and credentialed and accredited knowledge (Weber, 1978) are essential to professionalism for the 'nurturance of specialised knowledge' and therefore the occupational control of work (Freidson, 2001).

Although education has been regarded as the principal means to securing achieved social status in the professions (Larson 1977; Parkin 1979; Turner 1988), other factors such as a the ability and extent that professions can persuade the state, other professions and the public are equally important (Collins 1990; Macdonald 1989).

Key determinants such as power, wealth and client status are ordinarily linked to high status in the professions where specialised knowledge is required (Turner 1995). In contrast, lower status was ascribed (Leicht and Fennell, 2001) to those working individuals from stigmatised groups in society who were seen as social outcasts such as the elderly and those who were seen as 'dangerous'.

The value of specialised knowledge for Larson (1977) is rewarded with status and work where professionals can exercise their specialisms and therefore be autonomous, free from 'lay evaluation and protected from inexpert interface'. Specialised and superior knowledge depends on how a profession's expertise is valued by society enabling legitimacy to exercise control in organisations and over less able individuals on the basis that their knowledge could only be delivered by them. The relationship between occupations to one another in a division of labour and the forces influencing their jurisdictional boundaries provides economic gains but also social identity (Freidson, 2001).

For professions, the construction and maintenance of boundaries is crucial to preserve and expand boundary work which has been exacerbated by the influence of managerialism and marketisation (Cox 1991; Fournier 2001). Professional boundaries are comprised of knowledge and the norms, rules and values which socialise individuals into a profession and which have a social and cognitive dimension (Abbott 1988). When contexts change, new areas of knowledge or disciplines emerge and existing professions employ defensive strategies (Fitzgerald and Ferlie, 2000) at the boundaries to protect their claims to knowledge or reject claims to new

area (Nancarrow and Borthwick, 2005) to retain control, autonomy, identity and power to compete with other professions, the state or clients (Abbott 1988; Fournier 2000). The 'process of erosion of traditional boundaries' around and between professions and other groups can also 'reconstitute boundaries along which the professions can build new strategies of legitimisation' therefore enabling professions to continuously remake themselves (Fournier, 2000: 82).

Professions such as law and medicine have historically maintained power because of the knowledge they hold and the jurisdictions they carve out using their specialist knowledge. In response to changes in society and shifts in public sector work, professions and studies of them have attracted considerable research interest, such as in the medical profession which can be regarded as a 'traditional' profession (Eve and Hodgkin 1997; Fitzgerald and Ferlie 2000; Harrison and Pollitt 1994). Harold Wilensky (1964) in his paper; 'Professionalization of Everyone?' predicted that in time all occupations would become professionalised through the acquisition of esoteric knowledge acquired through education and training. The validation of these qualifications through universities and legal institutions would lead to what Wilensky (1964:146) called 'extraordinary autonomy' by certain occupations. This was later reinforced in Freidson's work on professions (1970, 1994).

Over the years the growth of medicine has caused the expansion and creation of multiple hierarchies of occupations and the dominance of medicine in the division of labour through possessing expert knowledge unavailable to the layman who has been unable to undergo the same specialist training and education, therefore creating

varying degrees of social distance between the provider of the service and consumer. This process of professionalisation can therefore be interpreted as a form of occupational control used to define the relationship between provider and client (Johnson, 1972).

Early work on professionalisation later resulted in Marie Haug's work and hypotheses of deprofessionalisation (Haug 1973, 1975, 1989). Haug depicted a process of deprofessionalisation where a profession's control and monopoly over a body of specialised knowledge would become challenged by a more educated public who demanded greater accountability of professional work. The increase in a more educated public would over time close the 'information gap' between the public and professionals because of an increase in the availability of technology leading to a public that were less willing to accept professional expert knowledge so easily. Haug (1974) suggests that as patients become more knowledgeable and challenge professional status, this would lead to a decline in the cultural authority of medicine and to changes in the relationship between doctors and their patients.

Knowledge therefore is central to professional status and claims and provides legitimacy and power to those who own certain types of knowledge. Haug (1974) however suggests that in time patients would become more knowledgeable which is what is evident in the NHS today where patients are increasingly challenging professional ways of work. Underpinning challenges to professional authority and indeed professions is knowledge; however these forms of knowledge and their association to power claims and status are changing, and subject to institutional

change, reforms and policies. This is evident in healthcare settings and policy where the patient is placed in a position to question and challenge medical authority and decisions. In healthcare then, the domain of medical knowledge is negotiated and open to contest.

Jamous and Pelloile (1970) have shown that central to a profession's claims to knowledge is not the technical context of their knowledge but the 'indeterminacy' of its implementation or the 'indetermination/technicality [I/T] ratio'. Their distinction is between technical knowledge, the type of knowledge that can be codified and shared with others, and indeterminate knowledge, that knowledge that cannot be codified and is more a feature of a professional's personality and history. Professionals and indeed medical knowledge is distinguished from other groups and forms of knowledge because of its indeterminacy and practical application therefore allowing the profession to exert control and power over its field. This ability to acquire and implement practical forms of knowledge plays a role in professional power and the ability of professionals to work in times of uncertainty where the ability to cope in times of uncertainty gives professionals power (Hickson et al. 1971)

These ideas of the characterising occupations provide a different perspective to what a profession is, that is, a profession's knowledge does not only have to be certified and credentialled as Weber (1978) explained. Rather, and as Jamous and Peliolle (1970) note, some work, or knowledge, can be clearly defined while others are left to the logic and judgment of the professional or worker. Professions then, are arguably

occupations with a higher I/T ratio (Harrison and McDonald, 2008) where the indeterminacy of knowledge grants professions autonomy and self-regulation.

Professions will also engage in discourses, for example in the medical profession, doctors will define, collate and apply expert knowledge exercising power over patients (Foucault, 1980). However, specialised forms of knowledge are now increasingly pursued by many occupations that were not previously thought of as professions and even by 'lay' people, such as patients who are becoming increasingly more knowledgeable about illness (Haug, 1974).

Freidson (2001:206) explains how, '...privilege for specialized knowledge deprecates the reliability and validity of everyday or lay knowledge and demeans the capacities of ordinary people' which is evident in the medical profession. Freidson's use of the terms 'lay knowledge' and 'ordinary people' were explored in the previous chapter, and with regards to specialised versus 'lay' knowledge in user involvement initiatives, it is in fact types of lay knowledge from ordinary publics which is seen as valuable to involvement activities as will be explored in the forthcoming empirical chapters. Challenges to clinical authority are evident, with changing roles and restratification within the profession, managers challenging doctors and a more knowledgeable public, changes supported by reforms at a policy level as discussed in the next section.

## **Professions in healthcare**

Ongoing changes and reforms across the public sector have altered the context in which professions work and seek to retain control and protect spaces. Changes at the micro level of the organisation along with institutional forces challenge professional identity resulting in jurisdictional disputes and the redefinition and restratification of professional roles. This re-stratification can lead to greater internal hierarchies and the emergence of individuals who claim and maintain elite status (Freidson, 1994). Within public service professional bureaucracies professional structures can provide the 'bases of power' creating opportunities for professionals to mobilise power and reproduce existing hierarchies (Nancarrow and Borthwick 2005).

The status associated with the medical profession is highly complex and located in historical and institutional bureaucracy where medicine is perceived as having a higher status than other professions (Timmons and East, 2011). Medicine therefore represents the quintessential profession within the field of health (Coburn and Willis 2000; Freidson 1970). Occupational boundaries in healthcare have been studied over the years (Hughes 1988; Mackay 1993; Porter 1991; Svensson 1996; Timmons and East 2011; Wicks 1998). Within healthcare we see how policy changes and reforms exert a regulatory influence upon existing power structures and professional associations by enforcing changes and new opportunities. Professional institutions exist and operate at the macro level and the micro agency level (Finn, 2008) where professional boundaries and identities are in a constant state of negotiation amid existing professional structures and institutional forces.

The medical profession gained dominance due to a number of factors including limited access to medical training for the wealthy elite (Nancarrow and Borthwick, 2005). Practitioners are able to exercise their power at the micro level in clinical settings over diagnosis and treatment in the care of patients, this however has changed over time as patients have become more knowledgeable and challenge decision making. In addition to power derived from professional knowledge, position or hierarchy, control is also enacted through a system of professions that act to block admissions by those whom they regard as subordinates. Doctors exercise power to reinforce medical certainty and control other subordinate groups by exercising control through the labour market (Freidson, 1986) and their clinical autonomy (Starr, 1982) and self-regulation.

Public service organisations, exemplified by the case of healthcare, are notoriously supported by the government which supports doctors' creation on a market shelter (Freidson 1982, 1986). The relationship the medical profession has with the state, in terms of self-regulation and state licensure at the meso level, and at the macro level where the medical model underpins medical practice and professional judgements that go unchallenged, have contributed to professional autonomy and control (Harrison and McDonald 2008:32). The impact of policy changes on professions will depend on the level of professionalisation, where knowledge elites such as doctors able to maintain their control and power over others (Exworthy and Halford, 1999).

The medical profession serves as an example of how professions restratify themselves creating intra-professional hierarchies (Freidson, 1994). Professions in



the public sector are exposed to constantly changing reforms and managerial intervention and influences with medical professionals rejecting changes and control of their professional autonomy (Calnan and Williams, 1995). Tensions are evident over disputed terrains where professions and the state are in a 'constant dialectic between autonomy and heteronomy' where management and the state seek to restrain professional control (Ackroyd, 1996) and professions attempt to protect their jurisdiction and power.

Added to this, changes in professional roles and workforce modernisation, work against existing traditional roles and hierarchies in healthcare (Young et al., 2001). The introduction of new roles and initiatives, such as public involvement and specialist practitioner roles, interact with traditional roles, professional identities and market closure strategies potentially causing workforce conflict and fragmentation within the medical profession (Currie et al., 2010; Freidson 1988). New roles in healthcare have posed considerable challenges to the traditional roles where exiting professional identities and jurisdictions may come under threat (Abbott 1988; Dent and Whitehead 2001; Currie et al., 2009; Freidson 1988, 1994, 2001; Larson 1979, 1990; Nancarrow and Borthwick 2005; Sanders and Harrison 2008).

### **Medical knowledge and changes in healthcare**

The monopoly of medical knowledge is being faced with significant changes due to the managerialisation of the system, increased consumerism and lay involvement and the move towards evidence based medicine (Allsop and Mulchay, 1996). The

managerialisation of the NHS has seen managers take control of areas where healthcare professionals had previously controlled. Managers have used their powers and control over resources to change how services are developed and delivered, as part of a policy push to managerialise working ways and liberate the NHS from bureaucracy and tradition (DoH, 2010a). Power dynamics are in constant flux owing to NHS reforms and the reorganisation and restructuring of professional roles. Although medical specialists have retained power and autonomy creating jurisdictions which are difficult to enter, policies around consumerism and public involvement have created substantial changes in the profession (Allsop and Mulcahy 1996; Thorne 2002) where the views and knowledge claims of doctors are being challenged (Strasser and Davis, 1991).

The development of new technologies and the managerialisation of healthcare have changed the character of the profession with competition between professions in the same strata. Evidence based medicine and new trends in health technology have given rise to the emergence of the knowledge elite (Freidson, 1984) and the rise of 'scientific-bureaucratic medicine' (Harrison and Ahmad, 2000: 138), contributing to stratification within the medical profession (Martin et al., 2009). Added to this, structural changes to healthcare fuelled by government attempting to use management as a solution to problems, have led to an attempt by managers to control and constrain resources resulting in doctors resisting and defeating them (Harrison and Pollitt, 1994).

Over the years changing health reforms have seen management gaining greater legitimacy to exercise control over clinicians (Harrison and Pollitt, 1994) including powers and jurisdiction in the selection of doctors (Thorne, 2002) and decision making over resource allocation. Managers were seen to use professionals to legitimise their decision making and solutions and as user involvement become an increasingly prominent area in policy the 'right' user was involved and so ticking the user box. As claims to jurisdiction change, managers form new powerful groups use managerial language and routines to gain acceptance and gain control over clinical jurisdictions (Harrison and Pollitt 1994; Thorne 2002). These disturbances in jurisdiction between the medical profession and managers, see each group attempting to acquire new 'turf' and stop the encroachment of occupations on their jurisdictions using their expert knowledge and skills.

The managerial and structural changes in healthcare and its effect on the medical profession and managers raises questions about the changes of power dynamics and claims to jurisdiction. Managers and executives are now increasingly starting to turn into 'professionals' using professionalisation strategies (Freidson, 2001). They are forming professional associations and developing educational programs which define and regulate the profession (Noordegraaf and Van der Meulen, 2008) enabling them to try to establish professional control in the same way as the medical profession historically have. Views that managers are an occupational group and have become professionalised have been contested (Mintzberg, 2004) but also acknowledged as a new occupational group that has established an occupational identity (Exworthy and Halford, 1999; Noordegraaf 2007).

However, doctors are now becoming managerialised to fend off management encroachment and are strategically using managerial techniques and practices in their professional work and identity (Waring and Currie, 2010). Professionals then are too being co-opted into management duties as part of their professional work to secure their autonomy and professional legitimacy. As such both managers and doctors employ different strategies to control expert knowledge and protect their jurisdiction where professional work is dynamic and subject to wider socio-legal and institutional forces. As well then as managers professionalising themselves using classical professionalisation strategies, management techniques too are being co-opted into professional work where professionals resist being co-opted into management roles and instead become competent in management practices (Waring and Currie, 2010). These changes pose a threat to medical professions' claims to clinical judgement and the rationalisation of expert knowledge.

The medical model of illness suggests that patient's health problems can only be addressed through medical expertise where medicine is the dominant medical profession. Patients then are seen to give up their jurisdiction of their body (Thorne 2002) to the doctor which then becomes medicalised (Frank, 1990) and which is reinforced through the belief that doctors possess superior knowledge. Abbott (1988) describes how doctors use their professional knowledge to maintain jurisdiction by providing adequate treatment to patients. He explains how for professionals, middle class clients were seen as more attractive because of their ability to understand their own conditions and 'relatively professional terms'.

However, policy calls for the involvement of users and collaborations between users and health professionals, where users are now situated in a place where their knowledge is required to improve service delivery. Service users for example, are more empowered through consumerism resulting in user consultation in service design and development (Germov, 1998). We now see examples of jurisdictional disputes and how healthcare professionals' jurisdictional boundaries are threatened by patient groups which are often dominated by 'well educated, well spoken and well off' and often middle class clients, i.e. possessing the same characteristics as the healthcare professionals selecting them (Church et al. 2002; Crawford et al. 2003).

A challenge for those involved service users is that they lack the skills and identity defining them as professionals or a professional group to provide them with credibility amongst health professionals. As we observe experiential knowledge of the illness appears to be of little value for those users who wish to exert authority and claim jurisdiction and it is suggested that users require 'other skills' and an ability to transform their experiential knowledge in a more valuable resource (Potter 2010; Cotterell and Morris 2012). For users to claim status then, they need to be defined more perhaps by some form of specialist knowledge rather than their laity, however there are contradicting policy imperatives to involve 'lay' users. This suggests that outlining user involvement as a democratic ideal to counter power imbalances and accountability by utilising lay expertise may prove to be difficult and unrealistic in practice.

The significance then of users' role is in its enactment and their ability to build an identity and skill base, in an environment where they are faced with power struggles and competition for jurisdiction from health professionals, managers and other users. Social movements for example were known for their ability to develop their own ideas and identities separately from service providers strengthening their capacity to engender change in health provision (Barnes and Cotterell, 2012). The self-organisation of social movements and groups outside state control then has enabled a space where users can exert power developing their own skills and knowledge. Individuals become part of a group because of a common set of shared beliefs and identity (Stryker et al., 2000) enabling a collective action. Groups seek to distinguish and compare themselves and discriminate against other groups in order to promote and enhance their own collective self-esteem and positive social image and evaluation. However, as user involvement has become mandated by policy and involvement activities respond to official agendas, users are sidelined by professionals, the credibility of their knowledge questioned and their identities as 'lay' users challenged by those playing the 'user card'.

### **Summary**

This chapter has reviewed the literature on professions and how professional status and knowledge are used as tools to gain, maintain and legitimise control over other groups. In carving out expert knowledge and drawing upon their education and socialisation professions seek to control markets and protect their space from being encroached upon by 'ineligibles'. Professionals delineate jurisdiction (Abbott 1988; Dent and Whitehead 2001; Freidson 1988, 1994, 2001; Larson 1977, 1979;

Nancarrow and Borthwick 2005) and draw upon their education and socialisation to claim positional power and status, which is predicated upon delineating a particular body of knowledge. Jurisdictional boundaries of professions in healthcare are threatened by service users who seek out scientific knowledge to contest professional decisions.

We observe in studies from medical sociology how activists, social movements and members of the public acquire scientific knowledge to challenge the views of scientists and the medical profession, leading to disputed terrains where some patients form strategic alliances with healthcare professionals for their voice to be heard and where professionals use patients as a tool to legitimate their decision making. In doing so, a divide is emerging in the user community where those involved may not necessarily be striving for the cause and a stratification of users is growing (Lakeman et al., 2007). In health provision, involved users lack the professional identity to gain legitimacy amongst health professionals and managers and so seek to construct one. Key points from the sociology of professions provide a useful lens to examine how service users delineate jurisdiction using an expert body of knowledge through a range of professionalisation strategies, enabling certain users to lay claim to power and status within the user community leading to a hierarchy of users and ultimately unrepresentative user involvement.

## **CHAPTER 4: METHODS**

### **Introduction**

This chapter describes the research methods and analytical process of the research including the choice of research design and process of data collection and analysis. Focusing on the process of user involvement, qualitative methods were best employed with the aim of examining how service users are involved in the user involvement process. I do not engage in extensive discussions on the different competing research paradigms which would be difficult to do justice (Benton and Craib 2001; Denzin and Lincoln 2005) but does describe the critical realist approach adopted. The chapter also includes how the cases were selected, the journey this took and justifies this as an appropriate approach to the exploratory research questions.

This chapter runs as follows. First, I explain the background to the study and its origin including the research questions. Second, I present the methodological approach taken including principles of case study research. Third, I explain how the cases were selected and the specifics of each case. Fourth, I describe the process of analysing the data. Finally, I provide a reflexive account of the research process and how this relates to the validity and reliability of the findings.



## **Background**

This study originated from an Economic and Social Research Council (ESRC) case studentship which began in October 2008. Empirically, the research was to focus on a range of innovation networks; a collaborative endeavour between groups of service users, health professionals and managers, and university academics in a particular subject related to mental health, under the banner of innovation networks operating in a mental health institute. Over time the study took a different direction. As with most doctorates, in my first year, I began to review the literature on a range of areas including user involvement, service development, communities of practice and public policy. Extant literature called for studies examining how users are involved in service development and how they contribute to service improvement and development. This was then to be the direction of my research. Into my second year I began to collect data on the innovation networks.

The innovation networks intended to develop evidence-based services to provide opportunities for collaboration between academics, managers, health professionals, the service user and carer community and any other interested parties. The innovation networks were established in an organic manner, and each network was provided with a small amount of money to carry out research. Each network had an academic lead and a non-academic lead (usually a clinician) and had to involve service users. The innovation networks covered a wide range of different projects relating to: education, employment, forensics, faith, music, research methods, social inclusion, dementia, social problem solving, recovery, acute services care, psychiatry and Attention-Deficit Hyperactivity Disorder (ADHD).

I conducted seventeen interviews largely with the leads of the networks and one with a service user consultant between June 2009 and February 2010. After preliminary analysis of the first few interviews I found that the interviewees, mainly the leads, spent a lot of the time describing what the networks were about and what they achieved, the latter focusing more on outputs such as publications, training and meetings. In later interviews, I attempted to pursue the question on service user involvement more and understand where and how involvement took place. I attended meetings of three different networks as a non-participant observer. The meetings lasted between one to three hours and were fairly formal with a set agenda. The members at the meetings included the network lead, academics, including students, individuals from relevant organisations and other invited guests. Audio-recording equipment was not be used at the meetings and only pen and paper was used.

Over the next few months and as the data was being analysed, it was clear that the process of user involvement could not be examined in the innovation networks because service users were not involved in large numbers. Rather, one or two service users who were known to the leads of the networks, individuals from third sector organisations, or service user representativeness were involved. Added to this, the networks were largely research focused and tracing users' involvement in the networks and in service improvement and development would not be possible. This case however provided me with two main insights into user involvement.

First, the involvement of users and the type of users i.e. the professional service users was led by the leads of the networks. Second, the few service users who were involved were not 'lay' users but more akin to professionals with insights from their service experiences. Although the results from this case were not used empirically in this work, it served as a methodological pilot for the other cases in that it helped me to understand who was appropriate to be interviewed and an awareness of the 'types' of service users involved. It also provided me with an insight into the complexities of involving service users and a clearer idea of my research questions for the next case. At this point, and into my second year, I felt that I needed to find another service development initiative involving service users to examine how service users were involved in service improvement initiatives.

Following discussions with my supervisors and a number of people in the local mental health field, I found a local Mental Health Trust had an involvement centre which involved service users in a range of initiatives. I discussed my research ideas with key individuals from the organisation who agreed that I could carry out my study at their two involvement centres. Spending three days at the involvement centre, as a non-participant observer, helped me to determine its appropriateness for a case study.

While the overarching aim of this thesis is to examine the processes of user involvement, the research questions set out in the introduction asked:

R1 What are the processes leading to the stratification of users?

R2 What are the outcomes of involvement processes?

From February 2010 and over the second half of my second year, I applied for ethics approval which was granted successfully. After I conducted a few interviews in the mental health case themes began to emerge, I considered that it would be useful to use another case as a means of comparison. I contacted a third sector organisation and although they agreed to take part, after initial discussions and meetings with service users and professionals, I realised it would be difficult for the service users to take part in the study because the state of their mental health was too fragile and sensitive.

Since user involvement in the innovation networks and at the Trust was organisationally led as a response to policy, I purposely selected another case which was not organisationally led and top down. I contacted the founder of a user formed and led stroke group who was known in the local health services. The stroke group was a bottom up user led group formed, led and run by stroke survivors. While another case would be different in its description (e.g. mental health and stroke or the differences in how involvement was set up), it served as a point of comparing similarities and differences in how user involvement was enacted in practice and the processes that gave rise to unrepresentative involvement.

I had initial discussions with him about my research which he then discussed with the other members of his group and I was then subsequently invited to a meeting to discuss the aims of my work with the group. When members of the group and associated individuals to the group agreed that I could examine the process of user involvement I then began to schedule the interviews.

A participant information sheet to inform potential participants about the study and a consent form to take informed consent was used in both studies. This allowed participants to speak openly and freely and discuss critical issues which were vital to the study and most importantly decide whether to take part or not (Glesne 1999; Miles and Huberman 1994; Silverman 2006). I began the scoping work for the cases in January 2010 while waiting for ethics approval and continued with data collection for the cases, including in-depth interviews, observations and document analysis, until March 2011 analysing the data along the way where possible. As Ragin (1997) states, this is common as 'case-orientated scholars use flexible analytic frames that can be modified in light of the knowledge of cases that researchers gain in the course of the research' (Ragin, 1997: 27).

### **Qualitative research**

I adopted a qualitative research approach where themes and patterns were interpreted and analysed, enabling theory to be generated and emerge throughout the study and also towards the end of the research (Pfeffer, 1982). The emphasis with qualitative research is that it focuses on, 'the perspective of those being studied rather than the prior concerns of the researcher along with the related emphasis on interpreting observations in accordance with the subjects' own understandings' (Bryman, 1989). Qualitative research was the appropriate method to use for this study because of key aspects such as; allowing events to unravel over time; taking the context into account, flexibility and lack of structure, and the use interviews and observations as primary sources of data (Bryman 1989; Pettigrew 1992; Yin 1994).

### *Case study research*

The use of case studies allowed the data to be collected longitudinally through various methods enabling me to understand how things evolved and why (Van de Ven and Huber, 1990). That is; the data consisted of stories detailing who did what and why and the events and activities which take place (Langely, 1999). Case studies provided insights and understandings into hidden areas within the context being investigated and combined methods including interviews, questionnaires and observations, which provided ‘experiential understanding’ (Eisenhardt, 1989).

A case study is ‘an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident’ (Yin, 1984: 23). Case studies were used in this study to gain a better understanding of the cases in all their particularities and ordinariness (Stake, 2005: 445) and as Yin (2003) explains ‘are the preferred strategy when “how” or “why” questions are being posed, when the investigator has little control over events, and when the focus is on a contemporary phenomenon within some real-life context’ (Yin, 2003: 1).

Case studies should be selected so that they either produce contrasting results or similar results; i.e. either literal replication or theoretical replication (Yin, 1994). Both intra and inter-case analysis were used in this study to illuminate key differences and similarities of context which affect the outcomes hence enabling generalisation through process analysis (Eisenhardt 1989; 1991; Langley 1999). It

was important to understand each individual case as well as the similarities and differences between the cases hence carrying out within-case and across-case analysis (Eisenhardt 1989, 1991; Yin, 1994).

The prolonged process and emphasis on context was beneficial to this study as it provided an analysis of the case studies where the main focus was on gaining an understanding of the processes which occurred within each case and individuals' views and understandings. The comparison of case studies enabled me to analyse why certain processes occurred in each individual case and across cases and to compare each case against one another to identify which aspects were common and different to each case (Eisenhardt, 1989).

In organisational studies case studies are extensively used (Grunow, 1995) to explore organisational change (Pettigrew 1985; Pettigrew et al. 1992), personal identity (Coupland, 2001), constructing narratives (Brown 1998; Currie and Brown 2003), and organisational culture (Bate 2000; Schein 1996), which would be difficult for other approaches to capture. This research can be seen as integrating ideas from the social sciences and healthcare where qualitative methods are adopted to examine the involvement processes. Cases were theoretically sampled consistent with Eisenhardt's (1989) method of purposive sampling and were employed to develop theoretical understandings. An extensive literature review, where key concepts and theoretical understandings were tabulated, and coupled with the research questions provided a springboard for case selection with the aim of extending theory or where possible developing new ideas (Eisenhardt 1989, Fox-Wolfgramm 1997).

Based on the aim of this work, and initial understandings of the complexity of user involvement in healthcare, qualitative methods using a case study approach was most appropriate. This produced rich data about the incidents and occurrences from each case and allowed insights from the social sciences to be used.

### *A critical realist approach*

Qualitative research allows issues which are unclear to be examined before commencing the research and is appropriate for open ended questions (Lincoln and Guba, 1985). It allows phenomenon in their local context to be explored as they change and emerge over time (Johnson and Onwuegbuzie, 2004). A number of approaches were considered prior to carrying out this study. Organisational studies often stem from a range of academic roots including sociology, psychology and anthropology (Knights and Willmott, 1997) and because of this a number of paradigms are used to examine organisations and change. While this study does not replicate any one exact paradigm or epistemological and ontological position, it does draw on a number of insights to produce the findings (Watson, 1997) and primarily takes a critical realist position (Ackroyd and Fleetwood 2000; Bhaskar 1989; Fleetwood and Ackroyd 2004; Reed 2005). Critical realism rejects positivism's preoccupations that phenomena can often be quantitatively measured, hence its preference for qualitative methods.

While critical realism compares knowledge claims and deconstructs them to assess their origins it rejects poststructuralist's (Willmott, 2005) and postmodernism's inclination that there is no reality independent of language. A critical realist



paradigm recognises that 'it is not reality which is socially constructed but theories of reality' (Pilgrim and Rogers, 1999: 19) and seeks to understand the relationships, events and discourses in the social world which are not always apparent and so require the work of social sciences to understand these (Bhaskar, 1989). In this work, a critical realist approach served best in understanding the social relationships and interactions between the various actors, where issues of knowledge, legitimacy, and identity were interconnected hence allowing multiple interpretations of the data to be compared and analysed.

### **Case selection**

Theoretical sampling was used to draw on comparative case studies (Eisenhardt, 1989) to examine multiple instances across cases using an inductive approach, utilising observations, interviews and document analysis (Bryman 1989; Yin 2003). That is; the study did not begin with a prior hypothesis or testable theory but rather with a set of broad questions from which themes developed and theories emerged. The method of theory generation was best suited to the exploratory nature of this study for two main reasons. First, a qualitative approach enabled the construction of a rich and detailed picture to be developed. Secondly, there were very few existing studies or theories to draw on which could provide the basis for comparative analysis or theory testing for user involvement in service development.

The choice of cases depended on what was known and how much new information was likely to be gained from the number of cases selected, the concepts which could

be confirmed and disconfirmed, whether the findings in one case could be extended and replicated across others; that is selection stopped when theoretical saturation was reached (Eisenhardt 1989, 199; Glaser and Strauss 1967). Eisenhardt (1991) argues that the concern however is not with whether two cases are better than four or one but about how much new information can be learned from the use of more case studies or incremental cases. I carried out an extensive literature review to determine the empirical research which had already been carried out and to understand differences and similarities to this study. I then tabulated the dimensions for case selections based on the gap in the literature and the research questions. The main dimension for comparison used to decide which case was relevant was if users were involved. For example, a number of potential cases were not used because users were not involved to a large extent or the involvement was for research or training.

Using comparative case studies (Eisenhardt 1989; Eisenhardt and Graebner 2007; Yin 1984) I set out to investigate the processes through which users were involved across both cases. The aim was to be able to generalise the findings from the case study material into theory in an analytical sense (Glaser and Strauss, 1967). This method facilitated a close correspondence between data and theory, allowing theory to emerge which was grounded in the data (Eisenhardt 1989; Glaser and Straus 1967). The departure point was based on an appreciation of the problems associated with the enactment of the “representative” user, as outlined in the extant literature, and so I aimed to build on existing theory as suggested by Suddaby (2006), to examine the processes by which user involvement becomes “unrepresentative”.

Preliminary interviews with key stakeholders from each case study were carried out to 'test' whether the case would enable relevant data to be collected and which demonstrated an initial link to the study aim, research questions and gaps in the literature. These surrounded the backgrounds of each case and the processes, which were seen to likely to affect outcomes; such as, the background of the individuals; the number of users in each case; the aim and degree of user involvement; how the group functioned, anticipated outcomes of involvement. Additionally, when cases were selected, practical issues were taken into consideration including the time available for the study, costs and accessibility.

The cases allowed me to understand how processes evolved over time and to piece together stories of 'what happened and who did what when' in each case and across cases therefore drawing out similarities and differences (Langely, 1999) with the variation in the cases enabled the development of new theoretical insights. Comparing the cases allowed a greater understanding of the specifics and idiosyncrasies of each case, and the variations and similarities between cases enabled deeper theoretical insights to be developed (Zartman, 2005). In addition, selecting those cases which were most practical and convenient in terms of time, cost and accessibility and which demonstrated an initial link to the study aim, research questions and gaps in literature were selected (Saunders et al., 2003: 177).

### **Case specifics**

Cases in two different healthcare settings were examined to understand if the instances which occurred in the cases were specific to the healthcare setting they

existed in or occurred across both cases. Mental health and stroke are similar in that they are both considered long term conditions which have been influenced by historic grass roots social survivor movements but are different in that mental health illness is usually physically unseen while the effects of having a stroke are often visible on a person.

In order to retain anonymity of participants (because there may be only one or two individuals with their role title in the organisation and they would therefore be identifiable) but without detracting from their roles, exact role titles are not included. For example, a social worker manager in social services, a manager in substance misuse, a matron ward manager, a team leader in drug addiction or a service manager in adult health services, is simply referred to as a healthcare manager. Because there are only a limited of number of people working in service commissioning in the organisations participants were interviewed from, service commissioners for stroke services from different bodies such as a PCT, county council or local network have not been explicitly identified to retain their anonymity.

### ***Mental health case***

The mobilisation of service users has been a prominent feature in mental health in England in the last 20 years (Barnes and Bowl 2001; Campbell 1996); being evident in government documents such as The National Service Framework (NSF) for Mental Health (DoH, 1999) stating that one of its core values is 'user and carer involvement' (Thornicroft, 2000). Mental health settings are often seen as being environments where users may commonly lack the knowledge and skills to adapt to

organisational settings of involvement (Harrison and Mort 1998; Simpson et al., 2002). As such, mental health is an important context in which to consider the boundary conditions associated with user involvement and its limits.

The Mental Health Trust case provides local services including adult, child and adolescent services, older people services, learning disability services and drug and alcohol services. Forensic services in the community and in acute settings are also provided to people in contact with forensic services. Involvement is a priority on the Trust's agenda and staff, service users and carers play a vital role in improving, modernising and reshaping services. The involvement strategy is implemented through a range of activities and schemes including the involvement centre which is run by users and the involvement team. All service user volunteers receive reimbursements for expenses incurred through their involvement such as transport costs but do not receive payments for their involvement work. The users who come to the involvement centre are usually but not always 'in recovery' rather than in the acute stages of their mental health illness and as such involvement initiatives are seen to aid in their recovery.

In-depth interviews were carried out with twenty-eight participants who had different roles (see tables 1-3), from January 2010 to March 2011. Table 3 outlines the roles and backgrounds of the different service users and carers to highlight the different routes users took to becoming involved. The degree of their 'wellness' is outlined but more exact details about the users' background could not be used due to confidentiality and ethics. These were carried out largely over two rounds, where

twenty one interviews were initially conducted and the data analysed, followed by a further seven interviews at a later date. Observations included four half day events each lasting between three and five hours and one meeting lasting about two hours. The half day events were made up of involvement activities where service users, managers and health professionals were involved and I was present as a non-participant observer. In addition to these, I fed back the results to the participants at the two different involvement sites in two separate visits.

### *Stroke case*

The Department of Health launched The National Stroke Strategy (2007b) to set a clear direction for the future of stroke services in England. Central to the ten point plan for action, the strategy highlighted how people who had experienced a stroke and their carers were to be involved as partners in the planning, design and evaluation of local services, service improvement and research.

The stroke case in this study is based on a user led stroke survivor group formed by a stroke survivor and run by about five stroke survivors. The group funds itself largely through membership fees and fund raising but the local PCT also gives the group a small amount of money for secretarial and administrative support in part, in the form of a 'lent' person from the PCT.

The group works with researchers, health professionals, managers and other groups to improve stroke services by providing insights from their experiences of stroke services and of having a stroke. The features of this case are particularly pertinent in a policy context which increasingly emphasises the importance of social

organisations operating outside the boundaries of the state. Since the group is not bound by state constraints and dependencies of centralised bureaucratic public services they are free to operate as they want and work with whom they choose.

In-depth interviews were carried out with twelve participants (see table 4), from January 2010 to March 2011. In order to retain some degree of anonymity, exact role titles were not included. I was a non-participant observer at two meetings made up of stroke survivors, academics, managers and health professionals, both lasting about two hours.

### **Data collection**

The research strategy involved collecting interview data, archival data and field notes from observations.

#### ***In-depth interviews***

First, following a number of preliminary interviews with stakeholders, semi-structured in-depth interviews were carried out in both cases, from January 2010 to March 2011, with a range of people within the remit of the cases including service users, managers, health professionals, academics and clinicians. Semi-structured interviews have been described as a 'type of conversation' initiated by the interviewer to obtain certain information (Cohen and Manion, 1989).

Prepared topic guides were used and interviews took place at various locations according to participants' preferences. Using topic guides to frame the interviews, whilst not limiting them, allowed them to provide examples of their experiences which prompted a wide range of issues to be discussed. Semi-structured interviews allowed questions to emerge from the conversations (Fetterman, 1998) from both the participant and myself as the interviewer and where necessary leave out irrelevant questions, include additional ones or provide further explanations (Robson, 1993). The interview questions included various aspects of user involvement including specific questions about representativeness, knowledge, legitimacy, the role and remit of user involvement, selection of users and the process by which users were involved. Before the interview, participants were given the opportunity to ask questions about the research, told that they could withdraw at any time and were given a participant information sheet to keep before written informed consent was taken.

Purposive and convenience sampling allowed rich information to be gathered which enabled the research questions for this study to be answered (Patton, 2002). Snowball sampling (Goodman, 1961) was also used where participants were identified when existing participants suggested other potential participants. In such cases, existing participants were asked to obtain verbal permission from potential participants before I made contact with them. This method led to additional lines of inquiry and reflects that the processes which were being investigated were not linear but consisted of 'twists and turns', typical of this type of research (Silverman, 1985).



The interviews were openly recorded and lasted between 45 minutes and two hours each. All interviews were fully transcribed. All data relating to the interviews were anonymised and confidential (Silverman, 2001) and analysed material was fed back to key individuals where requested allowing the analysis to be checked (Yin, 1994). Interviewing stopped when a point of theoretical saturation was reached, when interviews were only adding marginal increases to my knowledge (Eisenhardt, 1989) and the findings.

In the mental health case I carried out twenty eight interviews while in the stroke case there were twelve. There were two main reasons for the differences in numbers. The point of comparison for the cases was not a methodological one and was one of how users were involved in service development and so I stopped interviews after trying to interview everyone possible in both initiatives and reached a point of saturation. Of course there were also service users who did not want to be interviewed, primarily in the Trust case, in some instances this was because they were too unwell while in others they simply did not want to take part. Second, the size of the organisations in which the user initiatives existed meant that there would inevitably always be more people in the mental health case with it being based on a Mental Health Trust than the stroke case which is based on a user led bottom up initiative. In addition to this, the first round of twenty one interviews for the mental health case, informed the second round of seven interviews and also the twelve interviews conducted for the stroke case.

### *Observations and field notes*

Second, to supplement the archival and interview data I spent time in the field carrying out observations. A range of service users, carers, academics, managers and health professionals were present at the observations. During all the observations and meetings detailed notes were taken, which were later expanded and reflected on. Observations were key in helping me to ground the research questions in empirical understandings and experiences (Silverman, 2001). Before attending meetings or activities I asked for formal permission to be present and provided participant information sheets. At the beginning of the meetings, I was asked to introduce myself; I then explained the purpose of the observation and asked if anyone had any objections for me being there. Other than this introduction, I was a non-participant observer. Notes were taken during the meetings but were kept to a minimum in order to avoid any distractions. Following the meetings, I made more detailed notes about the meetings and my thoughts of them.

Field notes were also used to deepen my understandings and included details such as non-verbal interaction between individuals and the surroundings. These details could not be audio-recorded but contributed to the interpretation and analysis of the interviews and observations. Short notes included non-verbal communication and the surroundings. Expanded notes included my reflections as a researcher on the observations and interviews and notes of any areas to include in the interviews. The short notes and expanded notes as well as any personal notes were kept in a research diary. Keeping a research diary also enabled me to monitor my subjectivity

throughout the study and allow me to tell ‘...the story in meaningful, verifiable ways’ (Glesne, 1999). This increased the reliability of the research and to ‘trace the steps in either direction, ‘from conclusion back to initial research questions or from questions to conclusion’ (Yin, 2003: 105).

### *Document analysis*

Third, I examined the relevant National Health Service (NHS) and government reports (e.g. DoH 1992, 1999, 2001a, 2001b, 2003a, 2003b, 2004, 2005, 2007a, 2007c, 2008, 2010a, 2010b, 2011, 2012). These documents provided me with a background on the history of involvement and government legislations. In addition to this, I collected information, including meeting minutes and involvement strategy documentations, from the Trust, the stroke group and other organisations linked to the cases which had relevant information. Documents were a useful independent source of data and provided me with a background to the cases. Data analysis was an on-going process and began during data collection because the information already gathered influenced and informed the remainder of the research (Pope et al., 2000). Analysis was undertaken in an iterative and inductive manner (Miles and Huberman, 1994) but also deductively, where applicable, informed by conclusions and key concepts in the existing literature. Transcripts were read and reread allowing themes to emerge the data were analysed consistent with Miles and Huberman (1984) and Silverman (1997, 2000 and 2001). Each transcript and set of notes was read several times, generating and coding themes iteratively according to both issues identified in the literature, and features of the data that emerged inductively. For example, ‘representativeness’ and ‘the involvement process’ were categories or themes which

developed from the extant literature and so these codes were constructed deductively. Sections on interview transcripts and observational notes relating to this category were then coded accordingly. Analyses was therefore also driven inductively rather than solely based on the themes covered in the interviews from the topic guide, although throughout there were overlaps in the codes produced by both approaches such as 'service users representativeness'.

### **Data analysis**

Other categories such as 'knowledge' and 'professional' were constructed more inductively during and after the data were analysed. First order codes were then constructed from the broad themes and evidence from the literature, interview data, observations or document analysis attached to each code. For example, 'representativeness' was a theme supported by evidence from a range of existing studies. From this, first level codes were constructed such as 'power' and 'knowledge' which were relevant to the theme of representativeness. This theme in particular and the first level codes were supported by both existing literature and data from the interviews, where as other codes emerged inductively from the data relating to representativeness, such as 'service user consultant' and 'professional user'. Following the coding of the transcripts, data were then analysed in two main stages; preliminary analysis and systematic analysis.

#### ***Preliminary analysis***

This stage of the study was to familiarise myself with the preliminary data which was gathered and to decide how to progress with the analysis (Mason, 2002). From

the start of the study I identified initial themes in the data, using relevant documents and initial observations. Since the cases were longitudinal they were transcribed as and when they took place. Initial themes were marked on the transcripts and grouped together in a single document.

Throughout the data collection process and in the early stages of data collection I began to 'categorise' or code the data (Strauss 1991; Strauss and Corbin 1990) based on the secondary information I had as well as from data from the transcripts as and when they had been transcribed and constantly compared the data against each other (Pope et al., 2000). The categories consisted of small units of data or incidents and as the categories began to form I identified subcategories and different dimensions in the data. The interpretive approach allowed theory to be developed based on the 'grounded' words from the data gathered (Glaser and Strauss, 1967).

For example, during the preliminary analysis of the first few interview transcripts and data gathered from observations and document analysis, general themes began to emerge which were broken down into smaller categories. Ideas and emergent themes were also discussed, given the opportunity, with individuals who took part in the study as a validity check of preliminary interpretations of the data which at times also generated further data (Silverman, 2001).

I constantly compared the similarities and differences in transcripts in a single case and across cases allowing new dimensions or categories to be created which may have existed in one but not the others (Silverman, 2009). Codes were marked on the transcripts and once a theme started to emerge relevant categories for analyses were

created. By comparing information from different data sources new concepts which were not anticipated at the start emerged. For example, in one case the data from the document analysis suggested that user involvement initiatives were to involve a range of users in all areas of the organisation. However, the data from the interviews suggested that this was not the case allowing me to then further examine the reasons behind this.

### *Systematic analysis*

Following the preliminary analysis where initial themes were identified and a picture of the case began to come together, the interview transcripts were then analysed more systematically and in more detail. The data were further analysed and coded in categories following what Silverman (2001) describes as an analytical induction where 'phenomenon' within the data is identified and a hypothesis formulated about it. I began to look for emerging patterns and themes and analyse 'incidents in the data with other incidents appearing to belong to the same category exploring their similarities and differences' (Spiggle, 1994). This enabled me to describe the data and understand the relationships between and across different data and across cases.

Within case analysis allowed concepts and themes to emerge which were then systematically compared to the evidence from other cases to assess whether it was consistent across the others. Emergent relationships between constructs within cases were then identified and tested across cases to confirm or disconfirm the evidence (Yin, 1984). This iterative process and replication logic enabled me to identify how

closely the extant theory matched the emergent data hence shaping the theory (Eisenhardt, 1989).

When relationships were disconfirmed I sought to understand why this was which led to an extension of the extant literature, for example, the involvement process was different in both cases for a number of reasons; one case was in mental health and the other in stroke case, which could have suggested that the differences were attributable to the different contexts. Upon further investigation, there were numerous other reasons for this, such as the backgrounds of the individuals in each case, the involvement activities and the support structures in place. These findings were then compared to the extant literature to identify whether this was supported or not with previous studies. Literature which found similar findings increased the validity of the cases leading to wider generalisability and different or new findings led to extensions on current literature.

This was done both within one transcript to check for contradictions and inconsistencies and between transcripts to identify the different understandings different individuals had within and between cases. I also tried to identify patterns both within themes and between different themes. For example, a participant may have explained that they involved users when discussing their professional work but in another theme about user involvement a category emerged which highlighted that they did not involve users because of the difficulties in finding them. A theme which emerged across cases related to the difficulties of involving lay users. In the mental health case, participants explained that involvement was difficult because some users

were not trained to understand management jargon or understand what involvement sought to achieve. This theme emerged both within cases and across cases and I was able to draw out conclusions about the barriers and difficulties of involving different users. This exercise enabled me to identify contradictions and similarities within the different themes, categories and between transcripts and hypotheses were shaped and compared to conflicting and similar literature (Eisenhardt, 1989).

At this point it is worth discussing why I decided not to use any computer software packages to handle the data. I did begin to use N-Vivo 8, a software package used to sort and cross check data, but I found that it took concepts out of context and detracted from emerging developments. Richards and Richards (1991) propose that N-Vivo addresses many of the challenges of using software packages for qualitative research by aiming at theory construction and by providing a range of varied and flexible tools. When analysing qualitative data Glaser and Strauss (1967) warn against overusing coding at the cost of hindering emerging theory going against claims that coding and retrieve techniques are key to grounded theory (Goulding, 1999). As well as describing the benefits of using software for qualitative research, Richards and Richards (1991) explain that, '(t)he process of theory emergence requires a different ability: to see the data as a whole, then to leave data behind, exploring the lines of this segment of that text. To code and retrieve text is to cut it up...(t)he researcher's contact with data is light, hovering above the text and rethinking its meanings, then rising from it to comparative, imaginative reflections' (Richards & Richards, 1991: 260).



I found that it took longer to create categories and indexes using the software than it did to read through transcripts and identify patterns myself. The analysis was done in a Microsoft Word document using colour coordinated codes for different participants with hierarchical levels of analysis to order themes and sub themes. I found this analysis process without the software to be more analytical, flexible and familiar. My understanding and interpretation of the data was not simply confined to the interviews, it was also informed by the time I spent in the field and my notes and insights from this. Referring back to extant literature, reading emerging studies, transcribing, reading and re-reading interviews and while data was being analysed along the way all informed my ongoing analytical thinking

### **Validity, reliability and reflexivity**

With in-depth interviews and the complexity of data collection for case studies, issues of validity and reliability, due to the subjectivity of interviews and the possibility of interviewer bias, arise. In an attempt to minimise researcher bias and cross-check information to increase its validity, following the interviews, where possible, I discussed and reviewed findings with participants. Internal validity was enhanced by constructing case narratives and tables to summarise case data and to enable cross case comparison increasing external validity (Eisenhardt, 1989). Case studies allowed for 'methodological triangulation' where 'the flaws of one method are often the strengths of another' (Denzin, 1989) thus enhancing the trustworthiness, credibility, transferability of the data (Denzin and Lincoln, 2005).

Reflexive considerations are perhaps even more important to consider in healthcare studies and certainly this study because of the number of service users interviewed. Service users in mental health and stroke have had personal experiences with being both mentally and physically unwell and have been through services some of which may have not been a positive experience. It is often users who have experienced poor service provisions that are activists in involvement activities and so the relationship which is formed between the researcher and user can often be a very delicate one. Whilst interviews with service users were not about their personal experiences, it was inevitable that their feelings both positive and negative of services were intertwined in the interviews.

As an interviewer it was important for me to take the time to understand service users' experiences of healthcare services and be empathetic with their needs. Initial attendance of meetings as a non-participant observer provided me with the opportunity to understand issues such as this and served as an 'ice-breaker'. Recognising how my personal influence would affect the study (Patton, 2002) through the '...construction of meanings throughout the research process, and an acknowledgment of the impossibility of remaining 'outside of' one's subject matter while conducting research' (Nightingale and Cromby, 1999) was important. Throughout the study I attempted to remain as objective and as possible especially in circumstances where service users would attempt to use the interviews as an opportunity to discuss their personal health and negative experiences of health services. Continuous reflexivity and thinking ethically 'in practice' (Guillemin and Gillam, 2004) during the interviews and the research was a conscious consideration

along the research process. This was followed through in the analysis of the transcripts where a distinction was made between interpretive and reflexive reading (Mason, 2002) in the initial stages of analysing the transcripts where both explicit interpretations of, and implicit meanings within interviews and accounts of interviewees' views were considered.

### **Summary**

This chapter has outlined the qualitative methods used to examine the process of user involvement across the two comparative cases in mental health and stroke. Data were collected from document analysis, in-depth interviews and observations and was systemically analysed to develop themes and sub themes from the data. In the following chapters, the involvement process is examined in both cases in Chapter 5 and 6. Chapter 7 brings the themes together in a discussion. Finally, Chapter 8 the Conclusion summaries and reiterates the key points made in this thesis.

**Table 1: Mental health case: Role descriptions**

<b>Role</b>	<b>Role description</b>
<b>Service user volunteer</b>	Involvement in both general and strategic activities such as board meetings, training and chairing meetings. The depth and range of users' involvement depends on their abilities, training and desire to be involved. Service users are volunteers and offer their insights from their experiences of services where required across the organisations.
<b>Carer volunteer</b>	Involvement in both general and strategic activities such as board meetings, training and chairing meetings. The depth and range of users' involvement depends on their abilities, training and desire to be involved.
<b>Service user consultant</b>	Consults with academics, clinicians, managers and health care professionals on service improvements and research. One user consultant was involved in a range of activities across mental health organisations and supplied those interested with a contact card listing their title as a professional service user consultant
<b>Involvement development worker (also a service user consultant)</b>	Deals with involvement on a daily basis and ensures service users and carers are content, trained and involved in activities across the organisations. Originally a service user volunteer turned champion and consultant and now also an involvement development worker who is employed by the organisation and leads involvement activities.
<b>Involvement volunteer</b>	Supports service users and carers on a voluntary basis teaching them a range of skills such as IT

<b>Involvement support officer</b>	Supports service users and carers to ensure they get the most out of involvement depending on their abilities
<b>Involvement manager</b>	Deals with involvement on a daily basis and ensures service users and carers are content, trained and involved in activities across the organisations. Overlooks activities at the involvement centre and ensures the work they do and user involvement is fed into the Trust's involvement strategy.
<b>Senior involvement manager</b>	Oversees involvement strategies across the organisations
<b>Professional executive</b>	Oversees involvement activities to ensure that involvement is being carried out at all levels of the organisation and is benefiting all stakeholders
<b>Healthcare manager</b>	May work on patient wards or in clinical settings to ensure high levels of services. Involvement is usually integral to the role where service users are involved to contribute to service improvement and developments. Ensures that best practices and information around user involvement is shared amongst professionals. Raises the profile of involvement and works towards making it implicit in clinical practice. Captures feedback from service users about ideas for new user groups and how to improve patient care. May also be involved in managing case workloads for service users suffering from mental illness or substance misuse.

N.B.: All service users and carers work at the organisation on a voluntary basis and only get reimbursed for expenses incurred as a result of their involvement which are mostly travel expenses. The involvement development worker is now employed by the Trust, a role which many Service user consultants aspire to. Service user consultants may be offered to be paid by external organisations for their consulting services and expertise such as charities or academic institutions.

**Table 2: Mental health case: Interviewees and backgrounds**

<b>Interviewee</b>	<b>Role</b>
Will	<b>Involvement volunteer</b> Supports service users and carers on a voluntary basis teaching them a range of skills such as IT
Alice	<b>Involvement support officer</b> Supports service users and carers and carries out general administrative duties for involvement
John	<b>Involvement development worker/Service user consultant</b> Deals with involvement on a daily basis and ensures service users and carers are content, trained and involved in activities across the organisations. Originally a service user volunteer turned champion and consultant and now involvement development worker who is a paid employee of the organisation and leads involvement activities
Rhonda	<b>Involvement officer</b> Supports service users and carers to ensure they get the most out of involvement depending on their abilities
Mandy	<b>Involvement manager</b> Deals with involvement on a daily basis and ensures service users and carers are content, trained and involved in activities across the organisations
Craig	<b>Professional executive</b> Overlooks involvement activities to ensure that involvement is being carried out at all levels of the organisation and is benefiting all stakeholders

Joe	<b>Senior involvement manager</b> Overlooks involvement strategies across the organisations
Katy	<b>Healthcare manager</b> Works in a number of areas across the organisations in clinical work and management
Susan	<b>Involvement support officer</b> Supports service users and carers and carries out general administrative duties for involvement
Silva	<b>Service manager</b> Works in a number of areas across the organisations in clinical work and management
Beti	<b>Healthcare manager</b> Works in a number of areas across the organisations in clinical work and management
Millie	<b>Service manager</b> Works in a number of areas across the organisations in clinical work and management
Harry	<b>Involvement lead</b> Works in a number of areas across the organisations in clinical work and management to actively involve users

**Table 3: Mental health case: Interviewees and backgrounds (service users and carers)**

<b>Interviewee</b>	<b>Role</b>	<b>Background</b>	<b>Initial involvement</b>	<b>Activities involved in</b>
Max	Service user volunteer	Long term debilitating mental health illness, unable to be heavily involved	After being told about it by a health professional at a social inclusion function takes minutes of weekly centre meetings	Making tea and coffee and helping to prepare food for guest speakers at the centre
James	Service user volunteer	Long term mental health illness. Deemed by health professionals (and service user) <sup>2</sup> to still be in the mid stages of recovery. Previous experience of management routines and practices	Mentioned during an employment and training session at a psychiatric patients interview	Meetings, forums and focus groups
Joyce	Service user volunteer	Long term mental health illness. Deemed by health professionals (and service user) to still be in the mid stages of recovery.	Saw the involvement centre advertised in a local health magazine while waiting to see	Meetings, forums and focus groups. Beginning to show interest in becoming a

<sup>2</sup> Wellness and unwellness, the stage of recovery the service user was at, the activities they are involved in are broad to retain anonymity of interviewees and confidentiality.



		Previous experience of management routines and practices	the psychologist	service user consultant
Tom	Service user volunteer	Long term mental health illness. Deemed by health professionals (and service user) to still be in the early-mid stages of recovery. Previous experience of management routines and practices	Consultant psychiatrist told service users about the involvement centre	Meetings, forums focus groups
Jack	Service user volunteer	Long term mental health illness. Deemed by health professionals (and service user) to still be in the mid stages of recovery. Previous experience of management routines and practices	Had previously been part of local community groups for service users and gradually became involved at the centre	Meetings, forums and focus groups
Ali	Service user volunteer	Long term mental health illness. Deemed by health professionals (and service user) to still be in the early-mid stages of recovery	Saw a poster at a charity	Meetings, forums focus groups. Also involved in gardening, making tea, coffee and washing up
Chris	Service user volunteer	Long term debilitating mental health illness, unable to be heavily involved	Through a friend who used to go to the centre and introduced him to it	Making tea and coffee and helping to prepare food for guest speakers at the centre

Mary	Service user volunteer	Long term mental health illness. Recently joined involvement centre	Article in the evening paper	Making tea and coffee and helping meetings
Lola	Service user consultant	Long term mental health illness. Deemed by health professionals (and service user) to still be in the mid stages of recovery	Clinical specialist nurse suggested getting involved	Management activities, consulting, service improvement and development activities and steering groups
Kevin	Service user consultant	Long term mental health illness. Deemed by health professionals (and service user) to still be in the advanced of recovery. Previous experience of management routines and practices	Clinical specialist nurse suggested getting involved	Management activities, consulting, service improvement and development activities and steering groups
Adam	Service user consultant	Long term mental health illness. Deemed by health professionals (and service user) to still be in the advanced of recovery. Previous experience of management routines and practices	Has been involved in the user community for many years and the involvement centre was a place this user could use their skills	Management activities, consulting, service improvement and development activities and steering groups
Pati	Service user consultant	Long term mental health illness. Deemed by health professionals (and service user)	Through a health professional	Management activities, consulting, service

		to still be in the advanced of recovery. Previous experience of management routines and practices		improvement and development activities and steering groups
Evie	Service user consultant	Long term mental health illness. Deemed by health professionals (and service user) to still be in the advanced of recovery.	Has been in local healthcare for some years	Management activities, consulting, service improvement and development activities and steering groups
Chrissy	Carer volunteer	Has been in local healthcare for some years	Carer for son	Management activities, consulting, service improvement and development activities and steering groups
Kathy	Carer volunteer	Long term mental health illness. Deemed by health professionals (and service user) to still be in the advanced of recovery. Now a carer for family member	Clinical specialist nurse suggested getting involved when this user was a service user	Management activities, consulting, service improvement and development activities and steering groups

**Table 4: Stroke group: Interviewees and role description**

<b>Interviewee</b>	<b>Role</b>	<b>Background</b>
Martin	Stroke survivor / group founder	<p>Founder of user led group. Identifies himself as a professional service user/stroke survivor.</p> <p>Prior to experiencing a stroke this stroke survivor was a professional manager and company director and possesses extensive knowledge of management processes and routines</p>
Lisa Bob Paul Clint	Stroke survivor	<p>Experienced a stroke and now part of the user led group after being introduced into it by the founder of the group while on the hospital wards after experiencing a stroke</p> <p>Prior to stroke these stroke survivor held managerial and professional positions in both public and private organisation and possesses knowledge of management processes and routines</p>
Sara Lucy Sandra	Services commissioner	<p>Responsible for commissioning services in stroke across the city and county. Crucial to this are involvement activities where stroke survivors are involved to improve and develop services alongside professionals</p>
Miranda	Service development manager	<p>Responsible for encouraging professionals, patients, carers, to all work together to achieve what has been asked of them. Part of this is to involve stroke survivors and</p>

		work with health professionals and managers from other local health organisations to improve stroke services
Yvonne (Senior) Jenny	Health professional (clinical & management work)	Involvement in improving services and the stroke pathway by working alongside other health professionals, managers and stroke survivors as well we working in clinical care
Claire	Academic	Pioneers stroke care research where involvement of stroke survivors is central

## **CHAPTER 5: USER INVOLVEMENT IN MENTAL HEALTH**

### **SERVICE DEVELOPMENT<sup>3</sup>**

#### **Introduction**

As discussed in the previous chapters, user involvement can be seen as being paradoxical in nature in that policy and democratic rationales for involvement call for representative involvement but when enacted in practice involvement can often be seen to be unrepresentative and tokenistic involving only a select group of users. This first case study focuses on user involvement at a Mental Health Trust which includes learning disabilities and community health services. Guidance documents by the Department of Health including 'No Health without Mental Health: a cross-government mental health outcomes strategy for people of all ages' (2011) support the principle of putting recovery at the centre of mental health services and the economic and social benefits of supporting the health of the individual and their families, friends and support networks.

The case explores the processes by which users become professionalised and in turn unrepresentative of the wider user community. It contributes to user involvement and public participation literature by highlighting how it is not only professionals who marginalise certain users, but it is also a certain group of users who also perceive less able and articulate users are unable to be involved in healthcare decisions alongside managers and health professionals. This chapter runs as follows. First the case

---

<sup>3</sup> Much of this chapter is published in: El Enany, N., Currie, G., & Lockett A. 2013. A Paradox in Health Care Service Development: The Professionalization of Service Users. *Social Science and Medicine*. Volume 80, pp. 24-30.

background is presented. Second the involvement process is examined including how users are selected, recruited and trained. Third, the outcomes of the involvement are described. Fourth, user representativeness and the paradox of involvement are discussed. Finally, the chapter concludes by highlighting how the empirical findings contribute to extant user involvement theory.

### **Case background**

As a response to policy, the Trust developed an involvement strategy detailing that work should be carried out in partnership with members of the public, service users and carers, staff and partner organisations. The involvement strategy outlines that the Trust aims to work as partners with the public in decision making so that people can progress in their recovery<sup>4</sup> and stigma associated with mental health can be tackled. Mental health recovery was central to the Trust's involvement strategy where service users are encouraged to gain control of their lives by being involved in their own care and in service improvement:

'I mean if you break your leg, I mean you're interested in your care for eight weeks. [...] Mental health's a lot different I think because it's not eight weeks, it can be eight weeks and it could be 80 years. [...] I think you'll find more passion in mental health and learning disabilities and substance misuse, for the simple fact that it's a lot longer. And although you might have broke your leg, you can still function and do whatever.

---

<sup>4</sup> Recovery in mental health discourses is usually different from the literal meaning of recovery which usually refers to returning to a normal healthy life following an accident or illness. In mental health individuals or service users have the power to manage their own recovery where they adapt to their illness and go through a process of growth rather than a cure for all the symptoms, a process unique to all individuals (Weinstein, 2010).

Yeah, and you can still function, you know. Whereas if you've got a really severe or you know, a bad mental health problem you know, it's that debilitating you know, you can have your liberty taken away, you can be sectioned you know, you can be out there in the community and almost forgotten'. (John, Involvement development worker)

John, who is also a service user consultant, described how because of the long term nature of mental illness, the Trust invested in establishing an involvement centre dedicated to training users and ensuring that they are involved across the Trust in healthcare service improvement and development. The involvement centre offers a place for service users and carers to come to where they can share their experiences of mental health, and provides activities to involve service users and carers in planning, shaping and reviewing services. Support and training activities that develop effective involvement, are part of the Trust's involvement strategy where service users and carers are trained in communication, reading and writing enabling them to be involved alongside health professionals and managers. Involvement, then, is central to the Trust's work and is seen as essential to users' recovery but is also beneficial to the Trust in that the centre develops certain users who are then involved across the Trust.

By giving the public a 'voice', it is anticipated they will be empowered to work alongside health professionals and managers to improve healthcare services by bringing their personal opinions and views of health services. Service users found that involvement provided them with an opportunity to utilise their skills and help with their recovery:



'I went along to the Involvement Centre, gave them a brief outline of my skills in administration, numeracy, etc...[....] And they said 'Yeah, come and join us'. Instead it will give such an individual a sort of hope for the future, by giving them an avenue to build on his or her existing skills and knowledge. [...] Rather than having them sitting at home watching TV and listening to things like X Factor, which is a total waste of time. Also, in my case, since 1990, in our house we've never had a television. What's there for me to do? Read the newspaper all day? You're better to get out of the house and get involvement because otherwise I'm just going to vegetate.' (Tom, Service user volunteer)

Service users felt that a number of areas had changed through involvement but that there was still a big gap to bridge between the different professions and a 'them and us' culture where clinicians often forgot that they were 'working for' the service users and would continue to 'dig their heels in'. Part of the rationale for involving users was their democratic right to be part of service improvement and development. Service users described how they had aspirations like professionals and involvement gave them the opportunity to act these out in an environment where they felt empowered and also had a democratic right with legislations driving involvement:

'I mean if you look back at the Darzi Report the last couple of years you know, we've got a right to be involved in our care. And I think that's the same throughout the whole of the NHS.' (John, Involvement development worker)

By involving service users, the healthcare organisation could be seen to be fulfilling policy requirements but also giving users a voice in management decisions. Users felt they had the legitimacy to be involved in service development and improvement initiatives because it was their legal and democratic right but also because they had the knowledge of services which professionals could never have giving them the confidence to be involved alongside professionals:

‘I think the fact that service users now have a voice is one of the most powerful things. Because you can have the best psychologist or psychiatrist with all the letters after his or her name, everything and they could say right ‘This is the textbook, you’ve got this, this, this, this, you’re schizo-effective’. But at the end of the day, the only person who really, really knows is that person that’s been there.’ (Lola, Service user consultant)

Clinicians explained that involvement was difficult because service users did not understand about involvement activities and therefore could not effectively contribute. Service users expressed their concern about the lack of involvement opportunities in clinical areas and how clinicians were cynical that involvement could improve services:

‘Many clinicians still live in an ivory world, where we’re the men who are experts, we’ve done the degrees [...] we know what’s what. We will not accept users’ experience of life, users’ experience of the services and users’ experience of life. There is still that closed-door mentality. And ultimately that closed-door mentality, especially with all the changes that

are happening with the Trust, could lead to people falling through the gaps. So to a certain extent, I think there's clinicians there who are sat in their ivory towers who are not prepared to listen and need to get off their high horses.' (Tom, Service user volunteer)

Service users then were not only using their knowledge of services and mental illness but also had knowledge from previous employment providing them with the skills for involvement activities. Despite this, a number of users felt that involvement was still very low on the priority list for some professionals because of their workloads and the target driven culture and it was often the middle level professionals who would go 'astray' with involvement activities. Service users described how staff should be trained to work with them because this was an excuse professionals would use to create barriers when working with users:

'I think the other one is about training and education of staff and third sector and I think service users and carers have got a great deal to offer in training and development of staff you know because we know what it's like, we know what works. Yeah, when you're talking to someone about recovery and you know, a member of staff might be able to read ... you know, any academic in the world can have all the ... after their name you know, PhD or whatever but if you've not actually lived it, you'll never understand it. Whereas we do understand it and we can make a difference...' (John, Involvement development worker)

Service users found involvement gave them a voice and an opportunity to be part of their own care. Involving users in Trust activities such as on interviewing panels, where they would have an input into which clinician was best suited for the role, empowered them and helped their recovery:

‘...if you’re actually out there doing something useful and you feel like you’re contributing, your self-esteem raises and you become more alert because you’re in meetings and you’re functioning differently.’ (Joyce, Service user volunteer)

Service user consultants were encouraged by managers at the Trust to ‘train’ clinicians by describing their experiences of health provision. Since the users who were part of the involvement centre were unemployed providing them with a purpose at the organisation aided their recovery which saw a decrease in their visits to their psychiatrists and social workers:

‘It benefits the service user, carer, client, patient to recover and to move forward and to utilise services less frequently, therefore saving money...[t]hrough involvement and through the opportunities that involvement have put forward.’ (Kevin, Service user consultant)

### **The involvement process**

In this section the involvement process is examined to illuminate the processes by which service users and carers are involved. The findings suggest that professionals

'talent spot' users, train and educate them and then select and retain certain users for involvement activities. The themes are expanded on below.

### ***The involvement centre***

Service users and carers initially became volunteers at the involvement centre through a number of routes. These included but were not limited to, being referred by either their health visitors, introduced through family or friends, word of mouth through other service users, or by third sector organisations.

'I was a service user at [a district hospital], [...] well my named nurse at the time, [...] said I think the best place for you to go is to [the involvement centre]. I came in and I sat in on a Friday meeting and the power of the actual building and the people actually made me cry and I thought I'm going to go back there.' (Lola, Service user consultant)

Others heard about the involvement centre through advertisements in health centres, or were known to managers at the involvement centre and were asked to join the centre.

'I didn't know anything about the Involvement Centre until I was at a function with the Social Inclusion from (a mental health community health team). And there was a lady there from the involvement centre [...] mentioned [the involvement centre] to me and whether I would like to just go there for one day and just see what happens. So she picked me

up and brought me over to [the involvement centre] I was shown round by the manager at the time. And he showed me around, made myself very welcome. [...] I filled in an application form for the Involvement Centre and then started to go every week. (Max, Service user volunteer)

Following this, those who were interested (self-selected) or/and the involvement team viewed as being able to undertake training for more strategic involvement activities were encouraged to do so. These users were then involved across the Trust in service improvement and development, sat on management boards and attended professional meetings:

‘It’s not for everyone because even now, I think there’s some things perhaps a bit lacking. Like when it was first opened, service users thought it was a drop-in, going to be a drop-in. And it’s not, like the staff tell us, this is not a drop-in. You come here, you get involved in something and you do it. But that’s a bit much for some. They just want to come and be among people and relax and have a cup of tea. They don’t want to get their brain thinking about strategies and all this, that and the other, they really don’t.’ (Evie, Service user consultant)

Those users who were viewed as being less able, either because they were not as mentally well as others or because they would be less suitable to interact with professionals and managers at a strategic level (or both), were involved in less demanding activities such as talking groups, reading or gardening:

‘There may be occasions whereby you’re representing a group of people and then take it to another meeting, that’s a totally different thing, which I’ve not been asked to be involved with. Therefore you’ve got to take other people’s opinions into consideration. Well I think, I think that’s right in one context but also it’s also important to give other people a chance as well. Because I think if you start, you maybe, I don’t know if this is the case because we’ve not got to there but you may get to a stage where you’re sitting in and you don’t go any further. But maybe that’s the time that, you know, you look at other service user opportunities and that’s the next stage. That may be the case in that instance but everybody should have an opportunity to do whatever, if they feel able and [health professional and managers] think they’re able.’ (James, Service user volunteer)

One service user consultant described how he was initially asked to join the centre when it was being built and be involved in the design of the rooms. Over time this specific service user, who started as a volunteer, progressed to become a service user consultant, a more superior user role, following his training at the centre which coupled with the knowledge from his previous career enabled him to be involved in activities at a senior level:

‘[Mandy, the involvement manager] actually said to me ‘[...], do you think you could do this?’ And I said ‘Well I can certainly measure up’ because I come from an engineering background anyway, so that didn’t

worry me taking a tape measure and recording stuff. We had a plan of the building and all I did was just record every room's width and depth and what have you. And the width and the height of the door casings and stuff, just to make sure that we could get the furniture in that we were buying, you know what I mean.' (Kevin, Service user consultant)

A number of service users and carers joined the involvement centre through referrals from their health professionals (table 3, chapter 4). Kathy, a carer volunteer described how she was doing a course with a third sector organisation about being a carer and the lady who facilitated it worked for the Trust:

'She actually told me about involvement and she knew that I'd got a keen interest in mental health. She actually brought me across to have a visit one day and I had a look round the centre and met [John, the involvement development worker] and a few others and they told me what was available you know, what it was all about and to give it a try, and that's what I did.' (Kathy, Carer volunteer)

Other service users and carers who were known to the Trust from their work with third sector organisations or to individual health professionals and managers across the Trust were at times invited to be part of the involvement centre. Chrissy, a carer volunteer, had been a campaigner for carers' rights for many years and known to a number of health organisations, was asked by the involvement manager to join the centre when she knew of the impact she had made. Chrissy was an asset to the organisation in that she had knowledge of being a carer and a long history of



working with health organisations in involvement initiatives for both service users and carers. As Susan, the involvement officer had described:

‘All of our service users bring with them a depth of knowledge around mental health and trust services, which most of them will have received. Aside from the ‘service user’ experience, they also have their own set of skills that they can offer to the trust. There is no denying that some of the service users are more articulate, better educated and are further along in their recoveries than others using the centre.’ (Susan, Involvement officer)

The data suggests that professionals train and educate certain users at the involvement centre users ready for involvement, then carefully select and retain them, thereby creating a hierarchy of users.

‘You know, some of them who walk through our doors actually we can’t be a day service, we can’t be a day care because that’s not what we’re here for and we have to be very, very careful. But some of the people who do walk through the doors don’t want to do more than join a couple of the groups and have a coffee and talk. Other times it’s within three or four weeks somebody’s ready. And some are ready for work you know, some people who walk through our doors are, that’s where they want to be, work [...] ... there’s some who come to our centre who I don’t think will ever work. But you know, I do pick up on it and yes [...] when they

come through the doors, you can think I reckon that person would be really good in ... you know.’ (Rhonda, Involvement officer)

### *Training and education*

Service users and carers who came to the involvement centre were referred by various people or sources or asked to join by one of the involvement team, a health professional or manager. As well as the knowledge they had of mental health services, i.e. their experiential knowledge, they were then also provided with training and education at the centre to enable them to be involved in involvement activities across the Trust:

‘We’ve just designed the Involvement training, which I think is absolutely stunning. Which at a glance, you can see the sort of things we’re doing in the centre. And yeah, you do it without meaning to, you can pick out certain user because my argument’s always been not everybody who walks through these doors is going to be a peer support worker. [...]’ (Rhonda, Involvement officer)

For a number of users their previous work experience was an additional advantage and this knowledge was looked upon favourably by health professionals and managers because these service users and carers were easier to work with:

‘It was an advantage that we had previous management experience, so working in a strategic way came more naturally. Also the amount of information and the complexity of the information we were asked to

discuss and read, you needed to have a certain level of understanding.'

(Pati, Service user consultant)

Professionals argued that in order for users to work with them they first need to be trained and educated. Professionals emphasised that before being involved in meetings, users had to be 'ready', and the users who were involved in professional activities were once 'very different people than the people you see now'. Users were encouraged to learn new skills to enable them to be involved in professional activities:

'We've got people here that are not very good on computers, so we teach them how to become good on computers. We've got people that don't read and write very well, so we encourage them to do that as well. We encourage people to go on courses. But it's also about ... I come from an engineering background, from a management engineering background and I've got a lot of people skills and a lot of computer skills and I utilise those skills here.' (Kevin, Service user consultant)

A number of users explained how they were asked if they wanted to take part in activities such as, interview forums, management meetings, inductions and chairing meetings; those who were asked did and received subsequent training. However, not all users were ready for doing the training. The problem being that in many cases, professionals would 'talent spot' users and put those with 'talent' and ability forward for training and education; those users who did not fit the desired 'role description'

of professional and articulate, were more likely to not be involved in strategic activities. Pati, a service user consultant described how the involvement manager and involvement support officer 'do the headhunting':

'There's certain people that you get to know and you try and push them sort of thing 'why don't you come along to this I think you'll enjoy that why don't you come here etc...' (Pati, Service user consultant)

Conversely, for those users who were deemed 'ready', training and education, allied to experience, saw them employed more and more in user involvement processes and over time could progress to become a service user consultant. Users also underwent 'on-the-job training', run by the involvement centre to provide users with the skills and expertise required for involvement. Some users were more able than others and required less training often because of their prior work experiences; it is these users that progressed quicker to becoming user consultants or even employed by the Trust. Service users explained how it was crucial to be trained and ready for involvement because of how professionals treated them, often not on an equal 'professional level'. As well as confidence building, training provided users with a platform to demonstrate their abilities and skills and work alongside professionals where the more articulate user was seen as more credible amongst professionals:

'I've done a lot of training upstairs in-house training and it's all about being able to take it on. With me and (other service user consultants) you can give us a paper or something and we can read it and it doesn't sound like mumbo jumbo to us we can actually have an understanding of it but

it takes a long time, it's taken me 3 years now to reach this level even though I was like at this level a year and a half ago but to be able to walk into somewhere and even if I haven't got my ID with me for them to know 'oh yes [Pati] we know you're here' it's nice your face is known they know who you are...' (Pati, Service user consultant)

Not all users were 'able' to be trained and educated as they were either too unwell for this or did not possess the innate drive to progress to becoming a consultant and sit on management boards:

'You can give a person no end of training but they can be absolutely useless at the job when they come to it. We've all met them, we've all met people that have been trained and spent years training and got qualified but when it comes to the nitty-gritty of actually doing the job, they're no good at it, you know.' (Jack, Service user volunteer)

While those users who were seen as having the drive for strategic activities, were encouraged to undertake training and education to then be able to be involved in service improvement initiatives:

'[...] I have seen some people 'encouraged' to enrol whilst others are left to themselves. As you are probably aware with the low self-esteem of many service users, a bit of 'encouragement' is vital for most to take advantage. [...] [T]he 'encouragement' is based on the assumption of intelligence.' (Adam, Service user consultant)

### *Recruitment and selection*

Allied to the training and education was the idea of recruitment and retention. Clearly, professionals did have an idea as to which people were best suited for training to become more involved as users. Furthermore, through the processes of training and education, and continuous re-selection for additional duties, certain users became more and more skilled in terms of how to play out the role of a user:

‘...it’s a gradual process of going ‘ah that went well, that was good for me, now I can do this’...gradually seeing results from things and getting positive feedback from things....’ (Harry, Involvement lead)

Service users and carers who were trained at the involvement centre for involvement activities at a senior level were then chosen or self-selected by professionals and managers from across the Trust:

‘I think as Involvement has developed over the last few years I think the views sorted are from a wider perspective, from just one off’s to group and development work. [...] All in all I think that as things go moving forward involving [service user] consultants [are] a safe set off hands [and] was the norm, I now see more and more people moving forward and it’s not so inclusive. However for certain involvement activities you do need to know that someone can do and be part of that or you will set them up to fail, I guess what I am trying to say is it’s easy to just ask the same old same old, we/ I to put people on the pathway and if takes 2, 3, 4

years to get to consultant level then that's fine with me.' (John, Involvement development worker)

The above highlights the journey service user consultants make from joining the involvement centre as a volunteer to then being trained, and involved at a senior decision making level in the organisation. While this is not marginalising other users initially, over time the users who assumed service user consultant roles and who were involved in senior activities, were the same users over the years and failed to represent or be representative of the wider user community as explained below. Rhonda, described how users who were involved in senior meetings were able to do so '[...] after they've been with us [the healthcare organisation] for six months, a year, two years, they've been trained [...]' (Rhonda, Involvement officer). The involvement development worker described the start of his involvement journey.

'I was kind of encouraged to speak out. So one group led to two groups and two groups led to three and three led to four and before I knew where I were, I was actually chairing meetings.' (John, Involvement development worker)

Trained and educated service users, usually service user consultants, were encouraged to take part in management activities including at senior levels such as on board level, meetings:

'He sits at board level, in board level meetings, you know what I mean, a service user in a board level meeting, can you believe it? You know, it's ... I think five years ago that would have been unheard of but people

realise now that service users and carers or whatever you want to call them have the rights and the needs and the desires to be at these sort of levels and this sort of saturation.’ (Kevin, Service user consultant)

The above highlights an interesting tension in service user involvement. The ideal of having users fully involved may require a certain type of user, as defined by professionals, which may work against the ideal of the “representative” user. In essence, professionals may be happy to embrace the idea of involving users, so long as users conform to their idea of who the idea user is for involvement:

‘And yeah, there are some people who walk through the doors and you think you know what, you could be good. And you do push them. I might say to [Joe, senior involvement manager] ‘There’s a couple of real goodies at the moment, you know’. Like when we were looking for governors, I knew the ones that should go for it. If he’s got something important, if there’s something important coming up or there’s something needed, you know and I might say to him ‘You know what, I reckon we could...’ [...]’ (Rhonda, Involvement officer)

Related to the training and recruitment of users was the idea that not all users had the capabilities to be involved.

‘There is a mix of skill and a mix of people being at different stages of their recovery path. And that mix works well because certain individuals will take on certain tasks, other individuals will take on other tasks and



other individuals will just turn up for the meeting. And that's just how it is because that's how it is in life, you know what I mean, certain people aspire to do this, other people aspire to do this and other people aspire to do this.' (Kevin, Service user consultant)

Those users who wanted a greater degree of involvement were provided with training if they were mentally well enough. Nevertheless users who had previous management experience and were more articulate did not always have to undergo as much training and automatically progressed to 'higher ranks' in the user community and across the organisation. Not all users had the abilities and capabilities to be involved and professionals were aware of this and directed these users to different levels of involvement:

'If you put somebody like (Chris, service user volunteer) in a sub-committee or board level, you're wasting your time. It's no good for Sid and it's no good for the Trust. But there are a few people, like (Adam, service user consultant) and myself [...]' (John, Involvement development worker)

Rhonda, an involvement officer explained how some users were more articulate, confident and driven and it is these users who are often involved at management levels. Adam, a service user consultant, reiterated this view:

'...some people aren't as clever as others are they ... I've been blessed with innate intelligence nothing to do with me it just happened....I can talk quite well I've always had good English skills... I've always been interested in reading and writing I've always done that...so that's quite an important skill...being able to understand some of the papers...jargon...long words.' (Adam, Service user consultant)

As well as involvement activities such as mentoring, induction days and chairing events, there were also more strategic involvement activities which not all users were involved in:

'... there's two sorts of Involvement really; there's the Involvement that I'm involved with and then there's the strategic involvement that goes through to the directorates and they have to prove what they are doing within their directorate.' (Rhonda, Involvement officer)

The strategic type of involvement was usually where only those able and articulate users were involved who understood management routines and practices;

'I think involvement is more of a strategic thing...a lot of people think involvement is just about bringing people in because they don't like the wallpaper it's not. Yes it's nice...on the wards and the units some people are there for a long time and yeah it would affect them if they've got psychedelic wallpaper but that's just on the wards. I think with involvement [...] it's definitely more strategic it's more getting things

done making changes at a strategic level than anything else.’ (Pati,  
Service user consultant)

Service users benefited from being put through training and education and selected for involvement activities which ‘built up their CVs’ but user consultants specifically felt that they do the same work as professionals but do not get paid for this and while they felt the Trust appreciated them they felt they should be paid at times:

‘...[S]ometimes, it feels like we’re doing all the same work of what general managers and executives do but we don’t get the pay for it.... I know they’ve got the payments policy coming on board but it still doesn’t match personally the amount of work we do for minimum wage.’ (Pati,  
Service user consultant)

The above highlights certain tensions where service user consultants were given ID badges, access to Trust facilities and training, and at times treated as professionals but over time began to want the monetary benefits for their work which managers and health professionals had. Service users described how they were in a ‘unique position’ because of the experiences of services they had and their own mental health illness making them ‘expert’ in their own field. Service user consultants put themselves forward for involvement activities, and because these users were easily involved in management activities, managers and health professionals did little to recruit new users:

‘...we’ve found within involvement there are people who put themselves forward for more things and who may fit with what service managers are looking for from involvement. They’ll be someone who is more articulate and well-presented and the management will come to me and go ‘can you get this particular service user because we need to do this piece of work’, rather than ‘could you go to the panel and identify someone who wants to do this’” (Harry, Involvement lead)

### **Outcomes of involvement**

In the above sections we see how health professionals manage user involvement processes through training, education and ‘talent spotting’ certain users for more ‘strategic’ and senior involvement activities such as on management boards and consulting exercises. Articulate users were encouraged to repeatedly work alongside managers and health professionals, creating ‘different layers’ of users, where a user consultant or involvement development worker represented the ‘highest rank’ of the ‘different layers’ and one to which other users aspired. These users were happy to go along with processes that promote “unrepresentative” user involvement, particularly if they were one of the chosen few. These themes are expanded upon below.

### ***The professionalisation of users***

In the above sections, we see the work of managers and health professionals managing process of user involvement led to the exclusion of certain user but emergent in the data was the idea that some users were complicit in the processes that led to unrepresentative user involvement. A number of users expressed why

there was a need for the role of a service user consultant. Individuals drew on their previous work experience and expertise gained through training and education to argue for the importance of user professionals as opposed to representative involvement:

‘[...] just through his experience you know, he’s a service user consultant. And it’s because of the amount of involvement that he knows. But what people out there who will make them comments need to realise is that you know, people who have mental health problems you know, had a former life, some of them were doctors, some of them pilots, some of them you know, academics and you know, there’s a vast scope of people out there that have got a lot of experience.’ (John, Involvement development worker)

Service users described how certain professionals had the view that service users and involvement was a burden. A service user consultant described how one clinical academic would simply ‘go mad’ if a user volunteer was involved who was not talking or saying anything useful. As part of ‘proving’ themselves to professionals, user consultants knew that training and education would enable them to excel in their user roles. Adam, a service user consultant described that a lot of health professionals think users are a ‘nuisance’ unless they were able like him and he admitted that he knew they used him:

‘I think a lot of healthcare professionals think (service user volunteers) are a nuisance unless they’re like me. People (health professionals and managers) look up to us (service user consultants) because we become

one of them...you can do it you become one of them...they accept me on their level. They use me as a token a lot when they need a service user, in fact I'm probably doing the service user a disservice really because they use me, 'oh we want a service user on this committee...we'll get Adam' perhaps I should say no have Sue or Simon or somebody but they'd be scared to death you see they'd be absolutely scared to death...' (Adam, Service user consultant)

The professional service users defined their roles as requiring a large amount of drive and determination, which had led to them being given more and more work over time. In essence, they viewed themselves as being the 'high fliers' of service users, who were performing a role that would be beyond the competence of lay service users:

'I'm the kind of person that doesn't mind, I don't mind travelling, I don't mind being here, there and everywhere. But to get my job, you'd have to have the personality to do it and be driven. I'm a strategic person. The person who would get my job [as a user consultant] would have to be that kind of person.' (Pati, Service user consultant)

The rise of the user consultant, not surprisingly, created a certain degree of suspicion on the part of other service user volunteers who viewed consultant users as being undemocratic. Frustration was expressed that others were not offered the opportunities to get more involved, and that the system was at times promoting favouritism:

‘Sometimes I feel a little bit frustrated, in the fact that you don’t always hear of those things that some people are doing, in terms of you would have liked the opportunity to have done it as well. So there is a little bit about not favouritism exactly but kind of certain people that are doing a lot and some people that are not doing as much but perhaps they’d like to. Yeah, it ends up being the same old same old....[a]nd you know, maybe we could do with some kind of support group to come in and just talk about what it is we’re doing. Because people like (names of 2 service user consultants), we don’t really know what they’re doing else unless they tell us directly on a personal level. So we kind of like lose touch a little bit about what people are doing.’ (Joyce, Service user volunteer)

Service user consultants described how they inspire service user volunteers and they are looked up to because they were perceived as being one of the professionals. One service user consultant described how a service user volunteer aspired to be like her and even though she had more qualifications than her the volunteer lacked the innate drive to be a consultant. It became evident that a user consultant was the ‘highest rank’ of the ‘different layers’ and one which other users aspired to be like:

[...] he [the involvement development worker] was a service user, did the same as me. He came along, sat down, didn’t say anything to anybody because he was too shy and now three/four/five years on, he’s the

manager [...]. And that's proof of the pudding you know, that's what involvement can do for you.' (Kevin Service user consultant)

Service user consultants felt that professionals accepted them more as equals than they did user volunteers. The knowledge and expertise consultants had provided them with credibility and were therefore valued and respected to a greater degree by professionals:

'...[I]t's different because they know you've worked hard and they know that you work really hard and it is grasping that understand of how the Trust works of what needs to be done how things are done and going through the right procedures to get things done and training.' (Pati, Service user consultant)

We see then how the knowledge different users' claim, gained from their experiential knowledge of services, coupled with the training and education they receive through the involvement process, gave them the ability to be a user volunteer, or user consultant where each role licensed involvement in different activities. Users explained that because they worked at 'such high levels' within the organisation, working with professionals enabled them to go to professional activities, have diaries where they recorded dates of meetings and conferences, and an opportunity to learn new skills through training and education thus filling employment gaps in their CVs:



‘[...] what I saw with myself is it’s alright having your CV but like I say, you’ve got a three-year gap. Or like mine now, if I went into the general workplace, it’s not nearly a six-year gap, so with Involvement you can actually fill that space with training and it sort of bumps up your CV.’

(Pati, Service user consultant)

An involvement volunteer, who in a sense was neutral to involvement, not being a user or professional, explained that service user consultants ‘actually put themselves forward as user consultants and professionals’:

‘[...] maybe it’s a valid thing just because you’re a service user, and just because you’re a volunteer, doesn’t necessarily mean you’re not a professional [...] it’s all sometimes delusions of grandeur [...]’ (Will, Involvement volunteer)

A consultant user explained that he was put through training and he found that involvement work gave him the opportunity to ‘shine’ and feel confident. I asked him about his transition from a ‘lay’ user volunteer to a ‘professional’ or ‘consultant’ user:

‘[...] they [the Trust and professionals] made me a service user consultant that was very early on that’s quite early [...] I got really involved at that level and since then it’s spiralled [...] and I’m in so many things now it’s incredible I’m working five six days a week now because I do lots of emails on Saturdays and Sundays [...]’ (Adam, Service user consultant)

Service user consultants enjoyed the status that came with being a consultant and felt that professionals treated them as equals more than when they were 'just' volunteers. This cadre of users were always very willing to work with professionals and were very comfortable in management activities whereas other users who often had no previous experience in management felt uncomfortable or not up to the standard of professionals. Service user consultants described how they saved the Trust a lot of money because of the services they provided and felt they should get paid for this:

'...if went by about 64k a year probably saved them so I've saved them a hell of a lot over the average consultant wage past 3 years.' (Pati, Service user consultant)

Consultant users enabled professionals to utilise a skilled and articulate user in their activities whilst also 'ticking the box' that a user was involved:

'... I often wonder how much with those particular individuals (consultant users) how much the heart really is in it or how much is ticking those boxes. And I just get this feeling that a lot of the time it's ticking the boxes because they've got to do it.' (Will, Involvement volunteer)

### ***Professional jurisdictions defended***

Service users were involved in a range of involvement activities across the organisation, but only those users who had the professional skills and education were involved in more 'strategic' activities such as boardroom meetings, committees and chairing events. Professionals explained that involving the 'usual suspects' was

somewhat tokenistic but choosing the 'right' user was necessary because there were 'different layers' of users:

'...I think through training and experience...I know some of the ones who are consultant service users and they've been around quite a long time so it's like earning your spurs really they've done quite a lot they've had quite a bit of training they've got that confidence...and I think they are a fantastic example for people who are so have come into the involvement centre who are just starting to recover from an acute phase of ill health and to see somebody being able to do some of the things that they are would spur me on...it's like career progression. They might have their own agendas to some extent it may be to develop their profession which maybe not particularly reflect very highly so it's about credibility.'

(Silva, Service manager)

What emerged from the data were different user groups that categorised themselves based on the activities they were involved in which was underpinned by the initial training and education they received at the involvement centre. The following user consultant had worked closely with professionals after being trained and knowledge from past management work before becoming mentally unwell:

'[...] people [users] have gone along to meetings and they've come away disgruntled with the whole meeting. It's like oh they use too much jargon, it went straight over my head, blah-blah-blah. And I'm thinking well hold on, if you want to work at that level and you want to be

involved in that level, you've got to understand that level. And when they're doing their day-to-day job, they're going to go into their normal jargon-speak and using acronyms.' (Pati, Service user consultant)

This service user consultant was very in tune with management practices and felt that if users were not up to being involved at a strategic level then they should not be and simply let other users who were capable do the work:

'So they can't start reading out a very long sentence which they can shorten into an acronym, because that sentence is like 30 seconds of their meeting when they've only got 35 minutes to get the meeting in. But management can't keep going and going and going, because you'd make the meetings nearly three hours long when it was only supposed to be 30 minutes. And it's a resistance from service users and carers sometimes to learn as well. A lot of people (service users and carers) think they should have everything handed to them on a plate...' (Pati, Service user consultant)

Other service user consultants echoed this view and described how professionals cannot be expected to have the patience to deal with unresponsive users and although these users should be given the opportunities to 'come out of their shell' it was simply not feasible and involving service user consultant was simply easier:

'If they've got a meeting on and somebody doesn't say anything they can get irritated and think they're wasting their time...This is one of the things I battle on with, a lot of the service users say 'oh they shouldn't use long

words' and I say well they should you should learn the long words...I have arguments over that...' (Adam, Service user consultant)

The usual suspects were selected because they often proved to be the safe option and were already known to the organisation and to professionals and where lay users would bring their own agenda to meetings and ideas which were not in line with professional thinking. Therefore involving or 'picking' a user who was trained, understood management jargon and was known to the organisation was more convenient than involving a lay user:

'You know somebody is going to be good at speaking out and representing our centre and Involvement. And then you get the surprises, you get them that have sat there like a flippin' wallflower and been really...and then all of a sudden. To be honest, it depends who is accessing our centre at the time as to how much bitching and belly-aching and whizzwazzing goes off about who's doing what and how they're doing it. We did used to have rather a hierarchy of service users who thought they were certainly better. We do get the pecking order and we get an incredible amount of bitching and backbiting. It's natural. Well you get leaders don't you? You put a bunch of 20 people in a farm and you leave them alone for a month, without knowing it there is a natural...it happens, there's falling out and before you know it, there'll be some at the top and...I mean you have to be very careful what you say; we laugh because I mean the basic way I comment on it is, is that we get the raw material in Involvement.' (Rhonda, Involvement officer)

Beti described how as a health professional she was able to scan a room of service users and identify which users were able to be involved, it was almost like 'picking and choosing' but subconsciously at times:

'...[W]hen I was involved in a group setting it was quite easy but easier to recognise the skills or underlying skills that individuals had and how they could contribute into service involvement and whether that's right or wrong I don't know. Because there are some individuals that you felt actually I couldn't, it sounds really awful, but I couldn't kind of see where they could be involved or how they would represent the views of other people... it's where they are within their journey mental health or substance misuse and their stability as well I guess and also on a level of not intelligence but how they articulate themselves as well' (Beti, healthcare manager)

Pati, a service user consultant explained how she had the idea of starting a human library and after discussing the idea with professionals who realised it would be positive for the Trust's image, the idea was implemented. A number of ideas such as this largely came from those users who worked alongside professionals and who were often service user consultants who were seen as having intelligent ideas that would benefit the Trust. Adam, a service user consultant explained how professionals just 'took a liking' to him and how many years ago after his involvement in meetings, a senior health professional just labelled him as a user consultant and repeatedly involved him in activities.

Adam explained that he was able to carry out his service user consultant role, ‘...with ease and I think that’s what people want...without strain and stress we can just do it and people tend to like us...we get on with people with ease...’, he likened his abilities to a tennis player who could ‘just play’. Although Adam explained that he actually did not like the title of ‘consultant’ he did admit using it when he wanted something:

‘I tell you when I use it when I’m asking somebody for some money or applying for a job or I’m writing an angry letter if gives you some weight doesn’t it...’ (Adam, Service user consultant)

Like most service user consultants, Adam liked professionals wanting and needing him, and it was this and the status of being a consultant that drove them to keep putting themselves forward for activities. Pati, who had been a service user consultant for about three years, explained how she always had work to do and not all users would be able to do this. I asked her why professionals chose her to be involved in meetings and how they knew she would be able:

‘I think they take on that you are able to do it from conversations they’ve had with you...you can generally get a grasp of whether they and I don’t like to be rude or anything to people but what level of intelligence they’ve actually got or understanding...’ (Pati, Service user consultant)

Beti, a healthcare manager, admitted feeling guilty by keep asking consultants to do things because they were not paid for their role and were always busy, although she

knew they enjoyed the recognition of being consultant users. This was corroborated by a service user consultant:

‘I like being the first port of call when they need some advice I’ll get an email from someone that I’ve worked with in the past and they write me a little blurb saying ‘I want your advice are you free give me a call’ and it’s nice to feel needed and that is nice to have that communication that you feel part of something and part of the Trust...it’s just nice to be wanted really and valued...’ (Pati, Service user consultant)

Repeated involvement of service user consultants enabled them to develop their consulting skills, strengthen their relationships with professionals and enhance their own careers:

‘...people sometimes get caught up in using it as a way to develop a career and developing a professional identify and kind of using it as a stepping stone towards something else...[a]nd if you’re looking to involve the entire client (user) group in some way or represent their views it’s difficult because you only get the kind of people that would come forward and get involved in involvement work which is challenging. There’s certainly a political agenda around service user involvement, there’s a lot of pressure on services to involve people.’ (Harry, Involvement lead)

Evident then is how service user consultants felt they were more intelligent than other users and therefore able to work alongside professionals where understanding



management jargon and processes was central to involvement activities. Service user consultants described how users should listen and write things down rather than interrupting professionals and should try to have an understanding of the business world instead of taking a political stance to be involved with professionals:

‘I know because I’ve worked in business before I fell ill that you can only do certain things at a certain amount of time...you’ve got to do it gradually and the money that comes into it and finances so I have a good understanding of how finances work but like I said not a lot of people (service users) within involvement do its very few and far between that you do get those (service users) that understand.’ (Pati, Service user consultant)

Service user consultants justified their repeated involvement in part because they claimed user volunteers did not have the understanding to be involved in strategic activities and need things in a ‘very simple form’. This highlights that those users who are involved at a strategic level alongside professionals where inputs for service improvements and development are made were often service user consultants. The service users who were ‘unable to understand’ meetings and professional work were described by consultants and professionals as bringing their own agendas to meetings and were only concerned about their own lives and experiences in mental health services:

‘...you can’t have a meeting that takes on everyone because you’re going to get a few that’s in the room that understand it and then you’re going to get those that are putting their hands up every 10 minutes ‘what does that

mean, what does that mean, what do you mean by that, I don't agree with that, you can't do that, I've been through this bla bla bla' and they bring their own life things into it and it's like well 'I never got that I never had this, this is what happened to me' and then you hear about their life story. Yes their opinions matter but when it looks at the wider picture they're only a small...say if that happened to everybody then yes it would matter but if it's just the one occasion then it's something or nothing that could have been overlooked.' (Pati, Service user consultant)

The experiential knowledge service user consultants possessed but more importantly the knowledge of management processes they claimed, allowed them to legitimately participate in user involvement that excluded 'lay lay' users:

'It was based on the assumption by management that we were more intelligent than the others. Better communication skills and (one service user consultant) and I both have had experience in managerial roles. This helped in feeling easier in meetings. They were not interested in our mental health experience for our inclusion in their activities. We are a useful person to fulfil the service user slot without causing any bad effect on a meeting. This has had a lasting effect and I am still consulted as a kind of management consultant whilst also filing the role of a service user opinion and consultant.' (Adam, Service user consultant)

### **Service user representativeness**

Although on the surface involvement and the relationships between users were positive and cooperative, and to an extent they largely were, tensions remained between the different user groups which led to unrepresentative user involvement. This is expanded on below.

Opinions of user involvement varied with user volunteers largely believing that everyone could be involved while others, namely user consultants, argued that while all users could be involved a 'nucleus' of users had to drive involvement. One service user consultant believed that users who had a 'grasp on what's going on' should be involved because involving those users who did not understand things would 'scare the living daylights out of them':

'Because if you have too many chiefs and not enough Indians, there's just people doing nothing. And making decisions, you can't ... it's like if you have a group here and you've got six people and you ask everyone to sort of like make the decision for the group, unless you've got one person that leads and says 'Right, this is the decision we're going to make, does everyone agree?', after discussion, and everyone will go 'Yeah, alright then'.' (Pati, Service user consultant)

Tom explained that there had recently been a post advertised for a user to be part of a governing board and a user volunteer explained how although users [volunteers] want the 'loud-mouths' there he hoped there would be rotations every so often:

'Some of those who are the loud-mouths, it's all very well, we want them there (because they are voices for other users) but they shouldn't be there permanently because there are other people with views, which may be very, very relevant, based on good experience, which should be heard in order to direct service delivery... Well they've got life experience but like I said, there are courses which are run by the Trust, where you can train how to lead a group, group leadership, leading groups through all the activities. You can always tell the ones who want to be leaders. They're the ones who are more vocal.' (Tom, Service user volunteer)

Tom had worked in accounting prior to becoming unwell and although he possessed the skills to be involved in strategic activities his mental illness to an extent stopped him from doing so. Thus it was a mixture of qualities users' required; primarily an advanced degree of wellness as well as the ability to use their experiential knowledge of illness. Those users who were perceived as the 'right' users, were able to use their experiences from health services and their understandings of management processes and routines, in strategic and management involvement activities. Other service user volunteers including James and Joyce (table 3, chapter 4) were perceived as 'well' and able but did not possess the degree of management expertise and knowledge required for involvement at a senior level and so were undergoing further training.

Although the Trust's intention was to involve everyone, there were different activities for different users depending on how articulate and able they were.

‘They bring a vast amount of expertise and knowledge and skills and can support other people who are starting to learn that. So I think it is about getting a balance and being able to challenge ways of doing things, so that you know, people have been around for a long time, they should be open to challenge, as we as staff should be open to challenge and to say actually we might need to think about it in different ways. So I think it’s about creating a certain amount of dynamism within it, so it doesn’t...you don’t end up with three or four people doing the same things. But I think we do need people who have had you know, skills and knowledge and experience.’ (Joe, Senior involvement manager)

Kathy, a carer volunteer who was also moving towards becoming a consultant explained that it was not possible to involve everyone:

‘... [W]e won’t involve everybody because nothing involves everybody, nothing we do in life involves everybody, it’s all an individual thing. And some things work in pockets and nucleuses and stuff like that and that’s how we operate...So you don’t need hundreds of thousands of people involved in meetings...’ (Kathy, Carer volunteer)

A number of users and professionals felt that there should a turnover of those users who were involved in strategic activities. Although many users were still using mental health services most who were involved in management activities were in recovery and therefore did not have the same perspectives as current users. Despite

this, many professionals described how it was easy to use the same users who they were familiar with and who were trained and educated:

‘... [O]ne of the things that I think should change here is the turnover in service users. I think it’s very easy to keep the good ones you know, the ones that are really involved and you’re just not helping them though.’

(Susan, Involvement support officer)

This was also the view of Silva, a service manager, and of Beti a healthcare manager, who described how they involved service user consultants although their views could be quite stagnant and static:

‘ [...] we will use (Adam, service user consultant) quite a lot...but you are only getting Adam’s point unless you get somebody new coming in then that’s going to be quite static could become quite stagnant...you do need new people coming in and particularly I think in this because a lot of those people are still using the services but it’s also what people that are new to the services are going to be coming in with totally different perception impression whatever...if we’ve got sort of static then we’re not capturing that sort of thing and if those people are seen as on a pedestal and people think ‘I can’t achieve that so don’t even try’ (Silva, Service manager)

Service users can easily become out of touch with services because they are not using them in the same capacity as current service users who can add a ‘real voice’

to service improvement. Harry, an involvement lead, described how service user consultants would easily give their approval in meetings and it was less hassle:

‘...initially when we were doing involvement work here, management would come to me and go ‘we’re doing this piece of work can you take it to the panel, just get them (Service user consultant) to OK it and we can say our service users have been involved’...that’s not involvement, that’s tick boxing yes we’ve used service users...’ (Harry, Involvement lead)

Enjoying and holding on to their positions for long periods of time, certain users became more embedded in the involvement work and Trust making it less likely that they would seek paid employment outside the Trust:

...[Y]ou do have that core people and the staff will call upon those core people.

I mean if I can use (names 2 different user consultants), who’s quite heavily involved in all sorts of areas of the Trust, most of which I haven’t got a clue what she’s doing or whatever. But one of them is sitting on the Patient’s Council or whatever it’s called...I think she is being representative of all service users...[t]hey are both championing the cause of service users.’ (Will, Involvement volunteer)

Chrissy, a carer volunteer who was involved in numerous involvement activities who was known to be vocal about carer’s rights but who was not a consultant, explained

that all users have opinions and views and without involving them all, representative involvement cannot be achieved:

‘[E]ach service user and each carer has got a different view and aspect of the services and if it’s the same people every time, it’s ... they’re not really getting a true representative of the service users or the carers. The onus lies on really the Trust doesn’t it because it’s the Trust who chooses who they want to go on the board, on these different meetings and that. So it’s up to the Trust really isn’t it?’ (Chrissy, Carer volunteer)

Involving the same consultant users contributed to unrepresentative involvement but also led to them feeling too comfortable in their role and not seeking paid employment outside the Trust. Although service user consultants were needed by the Trust, a number of professionals expressed concern that these users got into a routine of work, enjoying it and feeling safe around other service users and professionals they know.

‘I have noticed that here, that it tends to be (names of service user consultants). But because as well I think they’re quite dominant people you know, they’re quite happy to stand up and do this, that and the other. I think a lot of it as well comes down to routine, they get in this routine and again.’ (Susan, Involvement support officer)

One service user consultant provided his account of his journey to becoming a service user consultant and is detailed at length to illustrate this:



Fortunately, I came right in at the start of Involvement and there were very few of us. So we were thrust into the role of the first service users to be involved with the decisions of the Trust...I was immediately thrust in with Executives and Associate Directors etc. We were treated like royalty so got off to a really good start. I was very well and keen to be involved with everything and always looking for jobs to do. I impressed which was quite a shock to me whereas the others didn't do this ... [A senior health professional] took me under her wing and really nurtured me... [she] appointed me as a Service User Consultant and she really invented the title, which has grown throughout the country. I got involved with everything locally and nationally that came my way and fortunately succeeded in people's eyes. I always work hard and have communication skills, especially written and spoken. I have been fortunate that I have read widely, always written and worked as a technical writer for ten years and worked part-time for local newspapers. That's where I was different. Others have not progressed and I'm not showing off, because of no fault of their own, others are not as well educated. They are also afraid to do things and take on challenges mainly due to low self-esteem but also lethargy...They do not get involved with meetings like we used too. They never sit in meetings with Execs etc. or anyone. They don't do any projects.' (Adam, Service user consultant)

In this construction above the user confirms how his role as a service user consultant was not only created, but also mandated, by managers and health professionals. The

user sought to gain legitimacy through the label of service user consultant, which was reinforced by professional support and encouragement from the organisation. In doing so the user differentiated himself from other users, whom he viewed as less articulate and less able. Eventually, he claimed a leadership position within the user community, which was reinforced by the repeated demand for his services in involvement activities from managers and health professionals.

### **Summary**

This chapter described how user involvement was enacted at a Mental Health Trust. For the Trust, the rationale for involvement was twofold; one to meet policy requirements and two to integrate involvement into service users' recovery. That is, involvement was seen as therapeutic for service users because they could utilise their knowledge of services coupled with the training and education provided by the Trust, to share their experiences and a purpose in the health system. Professionals described how they did not know who to involve and where to find service users which often led them to repeatedly involving the same users, who were often service user consultants. Involvement for many professionals became a chore while others described how they were cynical of the benefits of involvement.

There was an aspect where those who were well and who had management knowledge were the ones who were usually involved while those who despite having management knowledge and experiences but were unwell and unable to articulate themselves clearly were often much less involved. The particularities of this case and the Involvement Centre are central to this case in that involvement activities took place within a managerial framework. These managerial ideologies contributed to

the process whereby certain users assumed consultant positions after undergoing training and by using their experiential knowledge and previous management experiences in their service user consultant role.

A number of implications are evident in this case for user involvement. The lack of clarity about how user involvement should be implemented meant that professionals would seek users who were trained, articulate and who understood what was required of them in involvement initiatives. While a number of professionals had tried to involve lay users they found that these users brought their own agendas to meetings and did not understand management routines and jargon. Given the constraints of time and cost, professionals were unable to adapt to these users and reverted back to involving the consultant users. Also evident, was that while the aim of involvement was to capture lay opinions and experiences of health provision, it was users' knowledge of management processes and ability to interact with health professionals and managers which was most attractive. These attributes differentiated the in-group from the out-group, the service user consultants to the service user volunteers creating 'layers' of users and ultimately leading to unrepresentative user involvement.

Further, the discourses of professionalism amongst the professional service users was not limited to the possession of expert knowledge alone but was linked to their mannerisms, ability to deal with complex problems and uncertainty. It was these qualities and the possession of a sought after body of knowledge that privileged a certain group of service users with the position service user consultant. This process

however led to involvement activities being repeatedly dominated by the same service user consultants who were unrepresentative while also not acting as representatives for the wider user community. Their unrepresentativeness was such that they became unattached from not only the user community that they initially sought to represent but also from the services they were supposed to improve. These processes then led to the voice of the marginalised and disadvantaged being sidelined because those involved were the most well, articulate and able.

In short, the professionalisation process saw certain users take on the title of consultant mirroring the behaviours and attitudes of the managers and health professionals they worked alongside. Their experiential knowledge of the illness and services eventually became of little importance and rather their ability to understand and use management jargon coupled with their professional behaviour provided them with the legitimacy to be involved.

## **CHAPTER 6: USER LED INVOLVEMENT IN STROKE**

### **SERVICE DEVELOPMENT**

#### **Introduction**

In this chapter user involvement is expanded outside mental health and is explored in stroke to compare and contrast involvement in the two different health settings. In this case rather than the title of service users, stroke survivors is used to describe those individuals who have experienced having a stroke, are in recovery but given the long term nature of nature are still in receipt of various stroke services. Rather than being called 'service users' as in mental health settings, the term 'stroke survivor' or 'conqueror' is used. In this case, the stroke survivors or conquerors in this group disliked the label of service user with some finding it demeaning. Rather, they looked at the experience of having a stroke as a survival and conquest than a defeat with the label of stroke survivor being empowering. I use the term service user, stroke survivor and stroke conqueror interchangeably to describe members of the stroke group who have experienced stroke in this chapter as I do throughout this work.

The features of this user led stroke group are particularly relevant in the policy context which stresses the importance of social organisations outside the remit of the state (Norman, 2010) where a wider range of ideas and identities could be expressed. Operating outside bureaucratic public services enables these organisations and groups to retain their autonomy and at times still influencing public services. Social

enterprises and community leadership have been cited as integral to social investment and growth by the Conservative government where emphasis has been made to take away centralised power and control and hand it to local communities:

“Galvanising, catalysing, prompting, encouraging and agitating for community engagement and social renewal. It must help families, individuals, charities and communities come together to solve problems. We must use the state to remake society. We must use the state to help stimulate social action.” (David Cameron’s Big Society speech, 2009)

As described in a Chapter 4, this case was selected to examine how service users or stroke survivors were involved in service development; i.e. the process by which they were selected or self-selected by professionals and which users were involved. This case describes one where involvement was led by the members of the ‘bottom up’ group who sought to have a voice in policy making by addressing concerns about a democratic deficit where there is a need for the accountability of public services including in health care provision. Features of this case build on previous works (e.g. Barnes et al. 2003; Barnes et al. 2004a; Barnes et al. 2004b) which highlights the importance of examining the micro politics within participative forums where often the lack of imposed rules and structures can themselves exclude certain members of the public.

For these autonomous groups that operate outside state control, issues of legitimacy, collective identity, expert knowledge and representation of the public are important in understanding which publics are involved in public decision making. Motivated

through shared experiences of illness and social background (all were white, middle class, educated and had held management positions prior to stroke, often senior ones) these professional users define the remit of membership for their group, and through a process of repeated involvement and self-selection are complicit with health professionals and managers in unrepresentative involvement.

The chapter is structured as follows. First, the background of the case is discussed. Second, the involvement process including the creation of the group, formation and negotiation of identities and the development of a professional group identity are described. Third, issues of user representativeness and representation are discussed. Finally, the findings are summarised in a discussion of the chapter.

### **Case background**

For many health professionals and managers who came into post, the stroke group served as an existing reference group that were consulted in involvement activities. The group aimed to influence services by providing its insights and knowledge to health professionals and managers. Shortages in funding and a lack of resources made it an easy option for health professionals who would attend the group's monthly meetings and take documents which required a user's opinion. Rather than users having to be recruited for involvement activities and prove that they were able to be involved or require training, in this case professionals would have to bid their ideas to the user group:

‘They’ve also perhaps got an established group and management structure, so their agenda and opinions are a bit more proactively pushed forward onto the agenda than perhaps they might be for a PPI group in a different area.’ (Lora, Services commissioner)

The group were known in the local stroke services and amongst commissioners and managers who would look to the group for advice about stroke services and management issues such as funding, the feasibility of projects and how projects should be implemented. Service improvement and development was part of the clinical work in stroke services both at the PCT and the county council. Jenny, a health professional working in clinical and management settings described how when she came into her post, the user group was already embedded in the system and involved across stroke services. It was clear to her that the group was influential both locally and nationally and would regularly meet with the head of stroke rehabilitation services; she felt that this conveniently fit in with professionals’ work especially given the limited time to train and involve users:

‘I think having a group works well and we certainly as a service, we often use the stroke group as a sounding board for things like patient experience questionnaires. We’ll pass them through the group ‘What do you think of this? Do you think it’s a useful thing to send out?’’ (Jenny, Health professional)

The group would, for example, carry out observations of hospital wards and gather feedback from stroke survivors on the ward which was then fed back to health



professionals with recommended changes from the group. Time spent carrying out such activities by the group, enabled the service provider which the group worked with at times to save resources, by not having to employ health professionals and managers to do the same job the user group using their own resources while at the same time fulfilling management targets for involvement:

‘... it is a threatened area of our service development, I think it [the user group] ticks a nice political box and says we’re doing the right thing, and hey that’s wonderful, but actually sustaining it and getting some value out of it from both sides is far more difficult and not as tangible for everybody to get their heads around ..... and understand the value of that and what will it bring to the service and the patients as well...’

(Yvonne, Senior health professional)

The group also lent its expertise to research institutions and academics where involvement was integral to academic work by adding meaningful insights to research and in obtaining research grants. As was the case with health professionals and managers, academics also had ‘boxes to tick’ to secure research bids which were more likely to be successful if users had been involved in the research process:

‘Although Martin has involved me in various things where he feels that it would be helpful for me to wade in and say things. But my main interest with [the user group] is seeking their input into our research agenda and help develop further research from the joint partnership that we’re doing.’

(Claire, Academic)

Claire had met Martin at meetings about stroke services and because she was aware that there was no patient involvement, she asked Martin if he would be part of the research projects and research development she was undertaking. Through Martin and a number of other stroke survivors Martin introduced to Claire, a research group with a stroke survivor was constructed with Martin and Claire leading and running it. The partnership here resembles one where both Martin and Claire, worked in partnership while both pursuing their own personal interests. For Claire the group enabled research agendas to be carried out and for Martin involvement activities served as work that reflected his previous career prior to stroke.

Despite being small the user led group had made significant improvements in services such as in early supported discharge and the availability of transport for patients:

‘[...] two pilots were run and Martin’s group funded the pilots. And that then allowed the commissioners to see that it was successful and they then matched the funding and it’s now a service that’s ... So without his group, that’s one service that ... because there wouldn’t have been that initial funding if you like, to actually set the group going, to actually give you the evaluation to show the commissioners say ‘This is really good, this is evaluated really well, patients really want this ...’ (Jenny, Health professional)

## **The involvement process**

All members of the group had been in management positions prior to having stroke, were educated and middle-class, and identified their group as a professional user led group. These processes of identity formation and negotiation, and the involvement of the user led group in stroke services led to the marginalisation of the other users such as those who were less educated and less socially mobile. These themes are expanded on below.

### ***Creating a user led group***

All those in the user led group had experienced stroke in varying severities and at different points in their lives. Members who had not experienced a stroke were usually given membership and included carers, those engaged in stroke research or activities, health professionals and anyone who supported the aims and objectives of the group. Before this group Martin, the founder of the group, had formed and led a number of stroke survivor initiatives over the years including stroke forums, stroke service partnerships and action groups. Martin described his journey:

‘...I was persuaded to go to a meeting with the Chief Executive to talk about patient involvement. And we set up a Patient Partnership Group at [the city hospital], which I was a member of to begin with and then the Deputy Chair and then the Chair for something like four years. And as a result of the appointment of the Chair, I was a Board member on the Trust, but as a patient representative. I was asked to be a non-executive director but I declined on the basis that if I signed a contract of any

description, that prohibited me from being a free spirit and I wanted to be there as a free spirit. Then I retired from there and coincidental with all that, I'd set up [a stroke survivor] organisation, before I actually left the hospital ward. And that was me and the staff on the wards who I persuaded to join me, as a partnership, 50% was the theory but I was 50% of the patient then with the staff. And that took off in a big way. And then I was asked to join the [city] stroke forum as the representative from [the hospital].’ (Martin, Stroke survivor)

This forum was much wider and covered the county but there were frustrations because one of the key stroke survivors in the group expected that it would be easy to change services for stroke survivors. As a result of this, Martin met with members of the public and health professionals to discuss his concerns of stroke services and the forum, which resulted in the forum ending and the beginning of his user led stroke group. Martin, felt there was a need for a user led stroke group to change the attitudes of health professionals but more importantly influence stroke policy at a local and national level. His work with health professionals, hospitals, social care authorities and others who had suffered stroke coupled with his skills and knowledge from his experience in business enabled him to construct the group whose members acted as management consultants with experiences of the illness and stroke services.

Members of the group felt that health professionals and managers should not involve inexperienced users who were not able to understand management concepts including securing funding for service improvement because they would be unable to contribute to service development and improvement. This view not only

marginalised those who were perceived as less able but also meant that those who were drawn to the group and who Martin approached to be members, were all of a similar background and thinking.

For example, Bob a stroke survivor explained how he was used to standing up and talking to people and was articulate and it was these qualities which Martin saw in him. As well as other users lacking the skills and knowledge to be involved, members of the group explained how involving the masses would only lead to confusion and ideas being lost:

‘So I think somewhere along the line, you’ve got to have a few to make decisions in some respects because if you’ve got 40 people, every one of them are going to talk differently you know, think differently. So you can’t be responsible for everybody. But at least if you’ve got a reasonable mix and everybody’s had the same sort of thing.’ (Bob, Stroke survivor)

Operating outside ‘invited spaces of governance’, enabled the group to set their own inclusion and exclusion criteria for group membership and although it was ‘...supposed to be strategic’ it was also ‘trying to be a political party [...]’ Miranda (Service manager). This was further aggravated by healthcare professionals and managers who continued to use the stroke group as a reference point for involvement activities.

### *Constructing identities*

The group had been established over ten years and had strong links with the primary care trust, third sector organisations, managers and health professionals. As a result

of this, the group were relied on during involvement activities, predominantly those requiring articulate and educated users such as on management boards and committees. Bob, a stroke survivor in the group explained that his past management role for a multinational organisation provided him with the skills, knowledge and experience to be part of the group and work alongside professionals. The ability to work at such a senior level provided him with the legitimacy and ability to construct a professional user identity. He explained how this enabled him to build his confidence by talking to other professionals but stressed that only certain users had the 'personality' to be involved. This view was echoed by all the users in the group who described how they were able to work alongside health professionals in large part because of their past careers and not primarily because of their experience of stroke:

'I was UK sales manager for a Swiss company. So ... and before that I was in sales and before that I used to go ... I worked in a chemical plant. So all over that time, I was well used to talking to people and standing up in front of people. This is a big thing. A lot of people do not like to stand up and give a talk, without a doubt. Even a simple thing, a lot of people really don't like doing it. I think in that respect ... Yes, absolutely. Again, it's articulate. [...] whereas some people can be quite clever in what they do, they cannot explain it anybody else.' (Bob, Stroke survivor)

Clint, a stroke survivor recalled how he was invited to join the group by Martin after offering his support to raise money for the group. Following this, he attended group

meetings and began to offer his insights on how to improve stroke services using his knowledge from his management work before his stroke. Clint described there was a degree of elitism, bureaucracy and ‘bullying’ amongst the medical profession creating barrier to involving patients in improving patient care. He felt that the user group were respected and seen as legitimate source of knowledge because of their career backgrounds:

[...] ... being in business myself and being a director of a company, I would manage the Health Service in a completely different way to what it is managed. [...] you’ve got to manage bottom-up because you know, when you look at costs you don’t ...you can’t just keep ... you can’t just keep eliminating the service, in my opinion. [...] They seem to manage to think to make savings we have to get rid of the service that we provide and that’s not always the case in my opinion and I think it should be ... you should manage you know, there’s two ... do you want my honest opinion about the Health Service; it’s a crap management style. In my opinion. There’s nobody can make any decisions.’ (Clint, Stroke survivor)

The agenda for monthly meetings was set by the user group and health professionals and managers were invited to bring work along for the group to comment on. The professional backgrounds of the users in the group provided them with the legitimacy to be able to make comments on service development initiatives. Martin for example, described how clinicians should be trained with interpersonal skills and the ideal person to train them would be the sort of ‘elite lay person’ who had the

experiences of using stroke services but who was also articulate and able to provide training. The 'elite lay person' was described as someone from the user led group as opposed to a 'lay' user who was uneducated and did not have a professional background as they would be unable to bring any useful insights to involvement.

The organic development of the group enabled members to develop their own roles and operate in a space where they could identify their own boundaries, identities and positions in the system, without constraints from the state and health system:

'[S]ometimes it's also about the skill base that people have because I think within all of the national initiatives, there's been a built-in assumption that people actually have the skills. And actually there is a key set of skills that you do need to have or acquire in order to do work with local people and work on that level and do consultations and do all of those kind of things. There is a set of skills. But it's kind of been assumed that everybody has them.' (Sandra, Services commission)

The professionalism of the group and backgrounds of the users both attracted other users to the group who had the same skills and were from similar backgrounds. Professionalism here refers to the behaviour of certain service users which was compatible with that expected of and by managers and health professional including users' mannerisms and the ability to deal with complexity and uncertainty. Those users who did not 'fit' into the group's ideal user role joined other groups which this group described the 'tea and coffee' sort of groups; i.e. not strategic and professional or '[...] fundraising kind of things [...]' (Yvonne, Senior healthcare professional).



While for other users the group served as a progression from less professional groups:

‘So I’m just thinking of somebody as we’re talking that she had a stroke and then joined a local stroke group, which was much more sort of kind of low key stroke group and really about social support. But I mean she was a professional woman before she had a stroke and I think now you know, sometime after her stroke, she’s beginning to think about that she’s almost outgrowing that group in a way. And she is considering joining [Martin’s user group] because she’s quite interested in getting involved in that more sort of ... you know, that next level if you like.’ (Lucy, Services commissioner)

### *Developing a professional group identity*

For health professionals and managers involving stroke survivors was part of their job especially those working in service commissioning and improvement in order to capture what was important for stroke survivors and their carers. In recent years as a result of the increased deaths of people following a stroke, an awareness campaign was launched across the country to educate the public that stroke was a lifelong condition, affected younger people and was one of the largest causes of premature deaths in the country. As part of this and growing pressures from the public, the National Stroke Strategy (2007b) was launched detailing public involvement as integral to service improvement and development.

The members within the group were financially able to run the group largely using money from membership fees, their own personal finances and a small amount of money from the county council. Martin described how despite clinicians being qualified health professional and managers could never understand the experience of having a stroke and life after having stroke. Recovery, Martin believed, depended in part on the profession a person had before having a stroke; where those who had occupied leadership positions prior to becoming unwell were more likely to recover quickly but were also more able to be leaders in involvement and participatory activities. Central to the formation of the group was having articulate and educated users who would be able to influence services both locally and nationally. The group felt that only certain users were able to work with health professional and managers and given the cultural capital of members in his group, the ability of some users was ultimately more important and useful than others in service improvement and development:

‘[...] we then need to talent-spot in my view and we need to extract leaders from that group of people. And the individuals that are better-qualified to do that are clinicians who actually treat people because they should be able to spot what kinds of persons they are and what their capabilities might be as the stroke progresses. Having said all of that, I think it’s well known, the people that make the best recovery and therefore are the best potential recruits are the ones that are positive in their thinking and strong in character before they ever had a stroke. And I think there’s evidence to prove now that the ones that will make good

recoveries are the people that have those characteristics. So that's the sort of baseline that you work with. And amongst those, there are going to be a limited number of individuals that are real leaders. And they will be probably people that have had a leadership role in their past life.' (Martin, Stroke survivor)

The members of this group described how involvement was not about involving the masses or even having a representative sample, rather it was about involving only those users who were articulate, able and had the skill set to work with professionals. Owing to the skills of the group, local stroke services had over time become reliant on them and rarely considered using other users. And so it was that this expert group, formed and led by educated middle class stroke survivors dominated the user community in local service development and improvement.

While the backgrounds of the members coupled with their platonic bonds strengthened the group and facilitated their voices to be heard, there were implicit 'rules' for who was involved in the group and who was perceived as a legitimate member. Being part of the group provided the users with a professional identity which health professionals and managers viewed as an ideal voice for involvement activities:

'They very much see themselves as being people that influence commissioning and commissioning decisions and see themselves as very much being in that loop. Rather than a sort of stroke survivors groups

which is more about social support and you know, they don't see themselves as that at all.' (Lucy, Services commissioner)

The group was able to use their experiences of stroke services, management experiences and professional discourses to consult and advise professionals about how best to improve services. Involved in a range of initiatives, the group positioned itself as consultants to health professionals and managers on service improvement and in strategic committees where user involvement was 'by invitation only' because they were seen as 'professional' and able to understand management processes:

'A thing that we have done is bridged professionals and stroke conquerors [...] the point about having professionals is that you're sort of in awe of their professionalism and they would tend to ... [...] start speaking in professional sort of terms and all the rest of it.' (Eliot, Stroke survivor)

The management skills of the group enabled them to interpret information they were provided with but as they also emphasised having the condition and receiving the treatment for stroke gave the initial legitimacy to be recognised as equal partners. 'Lay' users were perceived by health professionals and members of the group as not being able to understand NHS jargon and having management experience was vital because it enabled them to understand NHS structures, principles, ethics and ways of working:

'[...] [M]any of our ex patients wishing to participate have a right to change, but need the correct calibre of management skills...we do have expert knowledge as a group but this knowledge is accumulated over a period of time, through talking to health professionals and learning from them, which is where the partnership grows alongside the respect [...]  
Finally you do need action groups wishing to improve their experiences, but they need to be joined by health professional with positions to make changes and most of all willing to listen, so it's not all about patient's intellect. (Clint, Stroke survivor)

And so through a combination of their previous work in management, the experiences of the condition and treatment of stroke and the knowledge accumulated over time from working alongside health professionals and managers in the NHS and wider health environment, the group was able to strongly position themselves as a professional group. They provided their expert knowledge, which was a combination of their knowledge and skills gained from their previous careers coupled with the experiences of the illness and stroke services, to professionals, where they were selected and self-selected for involvement and partnerships activities, while at the same time the group providing members with a professional identity which they once held before stroke.

### **Outcomes of involvement**

The rationale for involving the user led group for health professionals and managers was that the group was an easy reference group and understood management processes having knowledge of wider stroke services. For the group, involvement

served not only as an opportunity to improve services but also provided them with a platform to form a professional group. This led to the dominance of these stroke survivors who justified unrepresentative involvement by demonising other users as amateurs and carving out expert knowledge while constructing an identity of the 'right' user. These themes are expanded on below.

### *The professional user*

While the process of group formation and repeated involvement in service provision did not professionalise this group, it did contribute to unrepresentative involvement in that health professional and managers repeatedly used the group and the group put themselves forward to be involved. The knowledge which professionals sought from the group was not primarily their experiential knowledge of stroke but more their skills and knowledge of management processes and their ability to transform their experiential knowledge that was not subjective of their own experiences:

'I think they have to be confident and they have to have had experience of speaking in groups and knowing when it's appropriate to speak and when it's not appropriate to speak. The skills that we as academics and researchers and healthcare providers have learned as we've gone along, that sometimes it's important to make a point forcefully and not to throw your rattle out the pram at that point in time...So I think the leadership kind of role that Martin plays is ... can only really be taken on by somebody who has experience and has that sensitivity to know what's going on.' (Claire, Academic)

Martin's skills from his past career and experience of being in a senior management position and behaving in a manner that was compatible with implicit rules and routines of NHS managers, coupled with his extensive knowledge of stroke services was attractive to health professionals and managers who would often ask him to put forward ideas to his group and even encourage the group to use their own resources to pilot stroke initiatives:

'...Martin was also involved with the steering group that was driving the development of that, and that was both city and county. So if Martin has a particular you know issue about a part of the pathway that is the place to bring it up. Or if he ... you know, because he's aware of all the different aspects he's involved in, lots of different bits of the pathway, he's often ... I often go to him because he often has the biggest overview.' (Jenny, Health professional)

The construction of the 'right' user appropriate for involvement activities by both the group and by health professionals and managers was one who was educated, articulate and able to understand the wider context of stroke services;

'You've got to have that burning ambition. Well you've got to have [...] sufficient education I think to be able to reach that level. But Martin's got the education ... I think the key to Martin's success is he's been at the right level in his life. And he's therefore you know, talking to people within the NHS. [...] I've been directors of smaller companies; he's been

director of bigger companies and chairman of bigger companies [...]

(Clint, Stroke survivor)

The users in the group were retired and all had the financial means to run the group, attend activities across the country and promote the group as well as challenge professionals. This in itself meant that those users who were not socially and financially able as this group were marginalised and did not have a voice in involvement activities higher up in the system where management decisions were made. Martin, the founder of the group was specifically seen as the ideal user to be involved because of his extensive knowledge of both stroke and the health system:

‘The business aspect that [Martin] brings because he understands the bottom line. And unfortunately we’re in the days where healthcare is about the bottom line, so it is about cost, cost and benefit, and he really understands that. And he can talk to our service heads, to the chief exec, to the chairman, he can talk to them about that at their level, because that’s his background. So I think they have a much more meaningful conversation. Whereas, that isn’t to say I guess, I’ll contradict myself now that other service users haven’t got a valid voice, they have, but they come at it from a slightly different perspective.’ (Jenny, Health professional)

The ‘average’ user was described as being unable to ‘think’ like this group, they would not possess the leadership skills or management experience:

‘[...] the average person would necessarily think on those lines. They would pick up on the things that they felt were important to them at the



time or that were highlighted to them and they felt they could contribute to at the time, I don't think they'd do much more than that to be honest.'

(Lucy, Services commissioner)

The collective professional identity of the group provided them with the leverage to decide who to involve in their group and who was viewed as a legitimate member. The user group created a pattern where the voice of the 'ordinary' user was absent and where professionals sought to involve the group to meet management targets such as shorter meetings and quicker decision making:

'[...] our group flourished [...] largely due to the facts that we had the members we had and all of whom had particular skills and management experience that fitted our philosophy. We wished to be driven by our own agenda, which was to change the services we had experienced. This meant we had to be independent and expert in our subject. Although we were a-political, I suppose by the very nature of how health care is funded we had to be involved in politics but not as radical. [...] We certainly expected to be treated as experts and as partners on an equal level. (Martin, Stroke survivor)

The skills of the user group and their ability to work with professionals in an articulate and professional manner created social structures resistant to 'outsiders' who were perceived by both the group and professionals as being unable to be involved because of their lack of knowledge of the system and inability to understand the health system and professionals' ways of working. Users sought to

legitimate their role as 'elite' users by stratifying themselves as 'experts' compared to other 'amateur' users and over time became embedded in the system.

Added to this, members of the group had all had high salaries in their previous work and pensions and so could afford to be volunteers and run the group. Lisa, a stroke survivor in the group, described the members of the group as once being the 'movers and shakers' in their previous careers but because of stroke they were unable to continue with their professional work. Instead, the group provided each survivor with the professional identity which they lost because of stroke and enabled them to harness their energies and skills in service improvements and development initiatives, where '[...] the context might be different but the management processes are the same' (Lisa, Stroke survivor).

### *Professional jurisdictions defended*

Despite health professionals and managers claiming it was 'unfortunate' and 'sad' that the only way to involve users in strategic decision making was through the group they continued to use the group. In addition to this, because the group was well established in stroke services, many professionals found that the group enabled them to complete their work more efficiently in a shorter amount of time and more likely that it would be approved by management:

'...[A]ctually what him and his group are saying can be really quite powerful and I think commissions recognise and often very much agree

because we see first-hand what people are saying and why they're saying it.' (Jenny, Health professional)

As well as the group serving professional interests to meet involvement targets, it was in fact the group which would largely dictate what activities they would be involved in and in what capacity. For example, the group had refused to be involved in one research initiative because the researchers and health professionals wanted to involve a range of stroke survivors which were perceived by the group as being a waste of time as they would be unable to understand management jargon and research methods in the way their group did:

'I mean I think with involvement we are at risk with the sort of involvement sort of thing we have on everybody's agendas at the moment of tokenising it and basically saying 'Oh well on each group we'll have one or two people'. And you know, they do tend to be often the same people that crop up at every single group and go off all over the place...'

(Lucy, Services commissioner)

Able to span across different health services, work with different professionals and be involved in a range of initiatives, the group served as a source of information for health professionals that other users could not:

'[...] because he's aware of all the different aspects he's involved in, lots of different bits of the pathway, he's often ... I often go to him because he often has the biggest overview ... Because I'm not always involved

now with what's going on in the acute, so I don't know how that's developing but that obviously has a massive effect on what happens in the community because if they suddenly have a change of policy and decide to do something differently in the acute in terms of their discharge, that has a direct effect on how we work. So we need to know about it and sadly sometimes the only way we do know about it is through [the group]. Yeah, and that ... that I don't think is a good state of affairs to be honest, that's not fair on [Martin and the group] but he's ... it's a sign that we haven't got all the bits talking together [...]' (Jenny, Health professional)

For managers and clinicians who were faced with meeting targets, using this group provided them with the legitimacy to make decisions and put forward suggestions to senior management:

'...so it's actually who do you go and talk to if you want to get something changed because they can moan to me all they like or complain to me, but I ultimately don't hold the purse strings, I don't have any responsibility for how services are organised. I too can go to them and say 'In my professional opinion, I think this ...' and that holds some weight but often the patient voice is stronger with commissioners at the moment.' (Jenny, Health professional)

By repeatedly involving the group in research activities and service provision, other groups were not given the same opportunity to be involved which the user group were complicit in and where involvement provided them with the opportunity to utilise their expertise:

‘So people like Martin, who’s clearly done stuff on local, regional and national levels, he in a way is the equivalent of a CEO or somebody of that level doing their work. But the reality is that that’s the background he came from...You know, he came from that background, so it’s not particularly surprising that that’s where he finds himself now in the field of stroke but based on his background. He’s obviously had to work at that and he’s obviously had his own issues that he will have had to overcome both physically and mentally, in terms of having a stroke himself but you can see where that came from.’ (Lucy, Services commissioner)

Professionals and members of the group described that only certain users could be involved, that is, the legitimate user was one who was a leader, articulate, professional and who could work effectively with health professional and managers. A challenge for health professionals and managers was that the group would ‘pop up’ to be involved and ‘make themselves available’ making it easy involve the group:

‘It’s swings and roundabouts I think because I think you do get somebody that will drive them forward and drive their agenda forward [...] I think you have to be really careful that it isn’t their agenda that’s imposed on everybody else.’ (Lora, Services commissioner)

The group’s identity as a professional group and their strong links formed over time with professionals and healthcare services made their involvement easy:

‘... it’s almost easy to go to [the group], that’s the problem I am conscious of when I do my [patient public involvement] work. I am conscious that it’s easy for me to go to them, I know that I’ll go every month and get it tabled and get a response. And I probably know what the response is going to be because I’ve worked with them so long.’ (Lora, Services commissioner)

What transpired over time was that the group would be involved and other groups and service users who did not have the skills of the group were not. Described as a ‘force to be reckoned with’, Miranda a service manager, explained how the group sought to develop their identity as a strategic group who played a central part in the development of stroke services. As a collective the group excelled beyond other groups because of the skills the members possessed but also because the aim of their group was to improve and develop services and not simply fund raise or be a ‘tea and coffee’ group. Although the group was initially set up by Martin, over time other members with a similar past professional identity joined the group which was seen as a ‘consultative arm of the service’:

‘[...] like minded persons appeared to gravitate towards them, which, in some ways was to the detriment of the ‘non professional’ [lay] person, who’s opinions were not necessarily being listened to and their needs not addressed. For this group of survivors, [the user-led group] became an ‘out of reach’ and ‘out of touch’ group, with the majority of members having experienced a stroke many many years before. I believe that many people [other stroke survivors] could have been intimidated by the range

of professionals around the table, making decisions for the NHS.'

(Miranda, Service manager)

The mobilisation of the group outside state controlled spaces enabled them to use their dual identities, of patient and professional, to define themselves as an expert group and form strategic partnerships with health professionals, managers and powerful others to exert a degree of influence over stroke services. A lack of definition about what involvement was enabled groups such as this to operate outside the 'system' and led to the repeated involvement of this group. However, professionals repeatedly involved the group and the group put themselves forward to be involved leading to the exclusion of the less able and articulate user and a certain degree of elitism.

### **Service user representativeness**

Involving less articulate and educated users for these activities was challenging because they needed the training and skills for involvement activities as opposed to the group which was 'ready' for involvement. Lisa, one of the members in the group, explained that involvement would never be representative of stroke survivors because of the difficulty of finding users who had the skills to be involved:

'[...] how do you actually find people? And in fact ... and the trouble is also that what you do find is that they're all much of a muchness because they're the people who've got the time to do it. So they're mostly people who are retired, it's mostly men who do it because they need to be able to

feel that they're important still, you know. And you know, so I think it isn't representative then, no way.' (Lisa, Stroke survivor)

For health professionals, managers and other individuals looking to involve stroke survivors, the group was a much easier option and described as a 'necessity' because 'ordinary' users could not bring the expertise this group did unless they had extensive training and education but were justified as being 'the only option' in part because of large workloads and a lack of resources:

'I think it is difficult and therefore it is an effective way to do it because especially if we've got to make efficiency savings, we're not going to have the capacity to go out there all the time ourselves.' (Lora, Services commissioner)

While people in poorer areas and black and Asian people are more likely to have strokes than people from richer areas or white people (National Stroke Strategy, 2007b) this group were all white, educated and middle-class, and therefore unrepresentative of the wider user community:

'And it was part of my objective set for helping with Service Development was to look at being involved in groups that ... is to get public involvement in service development. Really with the view to getting hopefully a little bit closer to our Asian cultural people and our black people. Obviously [the user group] doesn't have those people in its group, but anyway that was a first start.' (Yvonne, Senior health professional)



Involving this group enabled professionals to save time in involving those users who would 'say things out of place' or bring their own agendas to meetings. The organisation of the group and its ability to mould to professional agendas led to their repeated involvement and the marginalisation of other groups:

'I think in the past when I've been involved with services [...] it's literally just you talking to the people that are coming through your service...you may see somebody that perhaps from their previous work life or their previous experience you think 'Yeah, they may have the necessary skills that would be useful for them to be involved in developing services'. So you may approach them and say 'Would you be interested?'...it is about training them up because they'll only know what they've experienced themselves [...] so them still going on about that issue is quite limiting really and not that useful for how you might then go on and develop your services.' (Jenny, Health professional)

Only educated and capable users were suitable for strategic activities at board level where involving a lay user was too time consuming and 'pointless'. One services commissioner explained that as part of her job she did have to involve a range of users in different activities and to capture different voices but always knew that to gain a 'strategic response' the group would be the only choice. Involving lay users was appropriate for activities she described required 'simpler engagement' but for activities which required managerial type insights she would involve the user group:

'And I think for us, what we need to do is to broaden our horizon and look at what else is out there rather than ... it's almost easy to go to [the user

group], that's the problem I am conscious of when I do my PPI work. I am conscious that it's easy for me to go to them, I know that I'll go every month and get it tabled and get a response. And I probably know what the response is going to be because I've worked with them so long. It'd be much harder if I had to go and source it and develop new relationships and work with people with different needs because obviously [in the group] everybody's quite articulate and you know, perhaps their needs aren't as reflective as some other groups.' (Lora, Services commissioner)

As a result of this selective involvement, the views being captured were ones of users from educated, middle class backgrounds excluding those users on the fringes of society. Users from the stroke group had the resources to mobilise themselves and fund meetings, transport and campaigns and ultimately had little or no voice in the system:

'I think where there's an issue or likely to be an issue is if you take on board the views of the most articulate people because it's easier to talk to them, and therefore you don't get anybody else's views at all and then you may have problems. Because clearly you're not being able to have any way of understanding what it's actually like for people and of course people's experiences are always going to be different...' (Lucy, Services commissioner)

This services commissioner went on to describe how the inequalities present in wider society and the social class system were reflective in the user community and

contributed to the pattern of the absent voice of many publics but it was difficult to mute the voice of the over represented such as those in the group:

‘If people come from a reasonably wealthy background to begin with, then regardless of having a stroke, they’re still probably going to be in that same category. Whereas you know, people who have perhaps been living a much kind of lower level life possibly are going to find it much more difficult to actually cope with the scenarios that they might end up with. You know, they’re probably living in the wrong house, wrong type of house, they’re probably living in an area that’s not on a decent bus route, so they can’t get anywhere. So they were fine before their stroke because they could walk or whatever you know and suddenly you’re just completely isolated.’ (Lucy, Services commissioner)

Although professionals could consult with other stroke survivor groups across both the city and county, Jenny a health professional, described how this would be difficult because other users would be less able and did not possess the professional mannerisms the group did. Despite concerns amongst professionals that the group was dominating the user community, little effort was made to involve others who were often viewed as a burden. Martin explained how user representativeness is impossible because only certain users can and should be involved:

‘I think that’s a utopian, naïve view. I think we should be looking for the candidates that offer the best expertise in terms of delivering this. And I don’t think that necessarily means everybody needs to be represented at

all. If we drew a business analysis or an example against this, we would say if we've got specific jobs to advertise that we need to invite the complete ethnic range. We would do that to begin with and then we would extract from that the ones that had the best expertise to do the job that we want to do.' (Martin, Stroke survivor)

Comparing involvement activities to business enabled Martin to justify why representativeness was not only unimportant but also ineffective. The lack of ethnic and social diversity within the group was not seen as problematic because for the user group involvement was about 'extracting' those users who had the best expertise to do the 'job' despite being unrepresentative of the user community:

'Well I found it interesting that the City Council do and actually most of the people in that group are County Council residents. So actually I think there's ... I don't know if there's anybody, hardly anybody in that group that actually lives in the city. So they're actually consulting with a group that doesn't even live there. Which is interesting, isn't it?' (Lucy, Services commissioner)

Managers and health professionals generally had to involve users in service development, improvement and decision because they were faced with meeting targets and so were more inclined to use the group who they were familiar with. Service commissioners generally had more freedom with involvement activities, more resources and less pressure with targets. Despite repeatedly involving the group there was concern about how representative it was:

'I think we do need groups like that, that feel comfortable in situations. And it would be nice to see a way of facilitating people to get to that point as well but you know, that might just be too much for them to take on really without support from other agencies...I just think we are in a bit of a tick box risk of just sort of getting one or two people on your group and then you just say that that's really. And easy to say you've done the involvement bit then.' (Lucy, Services commissioner)

Professionals explained that users who wanted to be involved had to know a bit about the health system because it added to their confidence but this usually meant that they were often just coming from a white and middle-class background. For example, one health professional described how she could not accommodate one user in her involvement activities because he would keep shouting out and demanding that aspects of the service should change that were simply not possible. Involvement here was 'pointless' because this user was not making a contribution to the activity and did not understand the healthcare system which was important:

'I think a lot of the time it's the time that's needed. I think people recognise now that in order to achieve what you want to achieve in terms of involvement and in order for it to be beneficial to those people who get involved, there are certain things that you have to do. And I think people often feel that they don't have the time to actually do it, so they may know in their own minds actually this is something that I ought to do but I'm going to scale it down to just this activity, which kind of gives me the ability to tick the box in a way.' (Lucy, Services commission)

While the group did represent a number of patients in some areas of their work, they were not representative of the patient community in strategic activities they were involved in. That is, the views and experiences they offered to health professionals and managers were subject to their own interpretations which were affected by their social backgrounds. Lora, the services commissioner, described that the 'high level strategy discussions' with the group were not representative of the users community and there was a need '[...] to quantify between professional patients' such as this group and patient groups who would reach out into the communities and work with families and their personal circumstances and experiences:

'From my perspective I feel that [the group] are not representative of all stroke survivors, in that its members were educated and able to articulate (even those with aphasia) their views and be aware of the gold standard of care they might wish to receive. I also feel that their socio/ economic positions maybe different to those of a population [of the city] and so they would have very different expectations to some of our local population.' (Lora, Services commissioner)

A paradox existed where involvement of the user led group was the easy option for health professionals and managers where the group possessed the skill set necessary for involvement activities but were always keen to be involved and had established their identity and legitimacy over time. Martin, the founder of the group explained how because of the skills users need to possess to be able to be involved and work in partnership with health professionals especially where they sought to make changes to services, a tension over who to involve would always exist:

‘There is always a tension and conflict between the motivation driving both sides. Policy and direction from the professionals and changes in the service from the patients and carers [...] [f]rom the patient side courage and confidence are needed from the professional side an acceptance that patients can be expert and very skilled. Then there is also the question of authority and organisational structure. From a professional point of view a hierarchy exists and there is no problem, from the other side there is no authority what so ever, one has to establish one’s own authority from respect and there is often no organisation to work through.’ (Martin, Stroke survivor)

And so while health professionals repeatedly involved the user group, because the skills and knowledge they possessed gained through their previous professional careers, was seen as essential in involvement initiatives, it was also the group who were contributing to unrepresentative involvement by continually self-selecting and where the opinions of ‘lay’ users or ‘non-professional’ users were not being incorporated into involvement activities where service development was taking place. As Miranda the service manager explained, those who ‘gravitated’ towards the group were from the very same backgrounds as those in the group leading to the selective selection and self-selection of what became a certain cadre of professional users.

### **Summary**

This chapter described the formation of a user led group and its involvement in stroke services. While the group was set up initially to support other users and

campaign for improvements in services, over time the group became a vehicle for its own professional work. Free from the spaces of public sector control and monitoring, the group sought to mobilise itself and decide who was able to be a member of the group and which involvement activities it wanted to be part of. Health professionals described that involving stroke survivors was often time consuming and difficult and using this group was easier to work with because they were articulate, educated and knowledgeable about health services.

Although the views of a range of users were represented in some of the work the group carried out, it was then subjected to the interpretation of the group; i.e. white, middle class and educated, where the views of other users were at times not only moulded into what the group perceived was important but also that which could be put forward to professionals and managers. While health professional and managers described how involving 'lay' users and a wider representation of the user community was the 'right' thing to do, they did little to do this explaining that this was often too difficult because they did not understand involvement activities, what was required of them and were not as articulate, able and educated as this user led group.

The repeated work with professionals and the experience gained from involvement activities, coupled with knowledge from their past professional careers, provided the group with leverage to decide where, how, and to who they would provide their services to. Not only were the group complicit in practices which led to unrepresentative involvement they also described how other users would be unable to effectively be involved alongside health professionals and managers not



possessing the skills and expert knowledge as they did. These processes of self-selection of the group and repeated selection of the group by those controlling involvement activities led to these users continuing to claim jurisdiction using their expert knowledge and repeated patterns of unrepresentative involvement.

## **CHAPTER 7: DISCUSSION**

### **Introduction**

The last two chapters detailed the cases of user involvement in two different health settings, one driven by a top down involvement initiative in a mental health Trust and the other a bottom up user formed and led stroke group. This chapter seeks to bring together the themes discussed in the empirical chapters marrying them to the literature discussed in the first two chapters, to answer the questions posed in the introduction chapter and throughout the literature chapters. In doing so, I aim to provide generalisable findings to contribute to studies on user involvement, while also illuminating the particularities of each case and the differences and commonalities between them.

The research questions set out in the introduction asked:

- R1. What are the processes leading to the stratification of users?
- R2. What are the outcomes of involvement processes?

In discussing the empirical chapters I aim to illuminate how these themes differed and were similar across the two cases. To answer these questions I set out this chapter to reflect the findings in the empirical chapters and centre discussions on three main themes; the involvement process including the selection and self-selection of service users, the stratification of users where I discuss concepts of lay expertise and expert knowledge and how service users defend their jurisdiction using their

knowledge and skills, and the outcomes of involvement, where I describe the professional user identity and the consequences this has to representative user involvement.

### **The involvement process**

While the two cases differed in how processes of involvement were played out in practice they shared similarities in the selection and self-selection of users and the ways in which certain service users sought to construct a professional identity and exclude others they regarded as too lay. In this section I discuss which users are involved and whose interests are being served by the involvement processes in the two empirical cases.

Across both cases rationales for involvement were mainly driven by policy initiatives to involve users, where there was an awareness that involvement was mandated by policy and in a number of professionals' roles written into their work schedules. As well as the rationales for involvement driven by policy, professionals also described how it was the 'right thing to do' because users would bring their experiential knowledge of health services to involvement activities. In practice however, it was these very insights and experiences which caused a divide in the user community with those users who brought their own ideas and experiences of health services to involvement being viewed as the ones who were 'too much work'. In practice then, the policy rafts for involvement were not played out, leaving an

implementation gap of what was expected of professionals and what was enacted in practice.

Exacerbated by a need to meet management and involvement targets, health professionals and managers involved those users who were known to them and the organisation and who had previous involvement experiences, in essence those who resembled a 'safe pair of hands' (Hogg, 1999). Not only was this implementation gap seen to be caused by a desire of professionals to meet targets, selecting those users who were known to them, but also by the self-selection (Church et al., 2002) of those users wanting to be involved which was evident across both cases.

Involvement processes then were overcast by processes of selection of those perceived as the 'right' user and self-selection of those wanting to be involved. What differed in the involvement processes in the two cases was how initial processes of involvement were controlled largely by involvement managers in the mental health case but in the stroke case they were mostly determined by users in the stroke group. Fuelled by an awareness that they had the legal right to be involved, users sought to actively carve out a space for themselves in involvement initiatives, not only as users of health services, but also as legitimate actors who possessed credible knowledge to be involved. Initially, processes of involvement in the mental health case were controlled by involvement managers, in that those users who were seen as 'ready for involvement' and able were selected for training and education. It was these users who were then later involved by health professionals across the Trust and who over time progressed to becoming service user consultants.

In the stroke case, we observe a different process initially. Since the group was formed and led by stroke survivors who shared common professional backgrounds and health experiences (Barnes et al., 2006), it was the users that created a professional identity for the group and decided who could be part of the group, creating an 'in group' and 'out group' or them and us which was manifested over time. Processes of selection and self-selection and ideas around what constituted credible knowledge were similar across both cases but these initial pre cursors to involvement differed because of the very nature of both cases; one a top down involvement initiative located within a mental health Trust and the other a bottom up user led group free from state control.

Explaining that only certain users could be involved, the group regarded other stroke survivors as unable to be involved leading the absent voice of a wider range of the public. Despite there being calls for user groups to operate outside managerially controlled spaces, this independent group created its own power dynamics and controlled which users were granted membership to their group. In an attempt to protect their jurisdiction at the micro level, this group of users deployed claims that their knowledge was superior and only professional or consultant users were legitimate actors in involvement activities. Given the backgrounds of these users, they were seen as attractive for involvement activities where professionals were pressured to meet management targets.

For those professionals working with the stroke group, involvement too was broadly defined and open to interpretation (Fudge et al. 2008; Rutter et al. 2004). This was

reflected in discussions with health professionals about involvement, where a number of professionals explained that they knew it was mandated by policy and they *should* involve users as part of service improvement initiatives but at times did not know how or where to and so turned to the stroke group who they were familiar with. The looseness of what involvement work entailed meant that managers and health professionals were '[...] free to take what they want from the guidance whilst deriving credibility from having the users on board' and leaving certain users the opportunity to benefit from the privilege of professional user status (Mort et al., 1996: 1137).

For the mental health users these processes differed in that the involvement centre was internal to the Trust and involvement was seen as integral to meeting political and legal requirements. Processes of selection and self-selection started in the involvement centre akin to processes in the creation and formation of the stroke group however the latter saw the processes governed by the group founder Martin and other members of the group. That is, group members were the gatekeepers of who joined the group and who then worked alongside professionals. With the mental health users, this process of recruitment and selection was originally largely controlled by those at the involvement centre but following the training and education certain users had the skills and confidence to then self-select themselves for involvement activities across the Trust, over time developing an identity as a service user consultant.

In common with other studies (Rutter et al. 2004; Fudge et al. 2008) there were blurred understandings of what involvement entailed, what users should do and how

they should be involved created a space where professionals interpreted how involvement should be enacted. While efforts were made to involve other users this rarely occurred and in most cases did not work because there was a lack of understanding about what was required in management meetings. Even if other users were trained, professionals doubted that they could be as effective in involvement activities as the 'professional' users because they would not have the knowledge or skills required. Professionals repeatedly emphasised how important it was for service users to understand how to be involved, that is, an understanding of the illness alone was not enough but also required was knowledge of the healthcare system and how it worked. The qualities which professionals described service users had to possess to be involved were ones which mirrored their own profession, knowledge of the health system, professionalism, education and an ability to work with health professionals and managers.

### *Selection and self-selection*

While the pre cursors to the involvement process differed across both cases, mainly because of the particularities of each case, the rationales for involvement were underpinned by the same principles; one of improving health services. As a result of the particularities of the cases the identity transformations the users underwent differed which will be discussed in a later section. The selection and self-selection of users and the types of knowledge and skills certain users brought to involvement were similar across both cases and it was these processes primarily that led to certain users claiming professional status and defending their jurisdictions leading to unrepresentative user involvement. This work shares similar findings with existing

work on user involvement around the paradox of selecting the ‘right’ users and the self-selection of those wanting to be part of involvement activities (c.f. Learmonth et al., 2009).

User movements in mental health, as with other social movements such as those campaigning for changes in health services for AIDs and cancer, are symbolised by their desire to change the ethics of science and to have a voice to counter the professional imbalances evident in science (Brown 1992; Brown et al. 2006; Epstein 1995,1996). What was evident in the processes of selection and self-selection in this work was how professional or consultant users did not engage in such campaigning and political struggles for user movements. In part this was because these service users in both cases were given a platform to be involved which was supported by policy and so knew they had the democratic right to be involved. Service user consultants in the mental health case and the user led group especially were situated at a strategic juncture where they were able to gain acceptance from health professionals and also from the user community. Instead however, for service user consultants, repeated selection and self-selection for involvement activities saw these users distance themselves from the wider user community, with service user volunteers explaining that they did not always know what service user consultants were doing.

While Epstein’s (1995) study described how some activists opposed their peers, suggesting that the former had become detached from the communities they claimed to represent by being ‘seduced by the aura of science’, there is no suggestion that



activists were pursuing 'insider' strategies or were 'co-opted' by scientists. In this work, users wanted to work alongside health professionals and managers as part of their pursuit to be seen as legitimate actors, but also because they aspired to move into paid positions in the organisation in the mental health Trust (e.g. involvement development worker or peer support workers). Mirroring the stratification within professions such as law and medicine (Larson, 1997), it is evident how users across both cases defined status using their knowledge of management structures and processes, while claiming other less able users were not credible or were amateurs (Currie et al., 2009) for involvement activities.

The user led stroke group had already become embedded in the system for some years, and had a voice, added to this the personal identity of the stroke users, that being white, educated and middle class provided them with the leverage to assert authority amongst senior managers and health professionals. This self-reliance of the user led stroke group gave them the momentum to act as a standalone user group, independent of health professionals and managers, but one which in fact was relied upon by a range of professionals. Service users had a desire to be perceived as being professional and carrying out professional work. That is, many of the users, especially those in the stroke group, had previously had senior management careers but had either retired from this or were unable to work because of their health, involvement activities then provided the members with a second career to use their skills and education.

## **The stratification of users**

The selection and self-selection of certain users gave rise to the emergence of different users. In the mental health case, users deemed as 'ready' for training activities and those wanting to undertake training and education were selected and then it was these users who progressed to be involved across the Trust in a range of involvement activities and specifically management activities. It was these users who were attractive to professionals because they possessed not only the experiential knowledge of the illness and of health services but also additional skills and knowledge from their previous careers which enabled them to work effectively with professionals. These latter skills and knowledge of management processes was seen by professionals as vital for involvement activities, more so than experiential knowledge.

The importance of such skills was more apparent in the user led stroke group where the group did not undergo training as with the service users in the mental health case, but rather utilised their skills and knowledge gained from their previous management careers for involvement activities. It was their knowledge of management processes which enabled the group to construct a professional identity and carve out jurisdiction seeing their repeated involvement and reluctance by professionals to involve other users who were perceived as being less able not only by health professionals and managers but also by members of the group. This echoes Martin's (2008b) work on public participation in cancer-genetic services where the experiences and skills users possessed were a source of legitimacy. Across both cases, involvement served as an opportunity for work experience (Ives et al., 2013)

and specifically in the stroke case, those involved users were more socio-economically advantaged excluding certain groups such as the marginalised and disadvantaged (Ryfe 2005; Wright 2013; Young 2000).and therefore unrepresentative of the wider user community (Wright, 2013).

Martin (2008b: 1763) describes how ‘from the users’ perspective, health professionals were characterising users’ input in terms of its alterity: as a biomedicalized or lay ‘other’ to clinical-professional expertise. In so doing, they were constraining the potential of user involvement by limiting it to an unnecessarily narrow conception of representative legitimacy, and missing out on the range of skilled contributions that users could make by drawing on the knowledge they derived from wider life experiences, including professional knowledge.’ In this study and in contrast, health professionals were very aware of the ‘range of skilled contributions’ users could make and it was this knowledge they brought to involvement from their past careers and from the training provided by the Trust, that was seen as crucial to involvement and which led to the stratification of users and the marginalisation of the less articulate and able user that existed within a managerial framework.

### *Lay expertise or specialist knowledge?*

It was evident that the processes of selection and self-selection depended on what skills and knowledge users could bring to involvement activities. In line with other studies this work also illuminated how professionals picked those users who were known to them and that those wanting to be involved put themselves forward for

involvement activities (Hogg, 1999) and who was usually articulate and educated in understanding management processes (Learmonth et al., 2009; Martin 2008a, 2008b). Even those users who possessed managerial knowledge and experiences but who were in the early stages of their recovery were not seen as the 'right' users. Therefore, the 'right' user was perceived as one who was well and who also possessed the knowledge and ability to translate their experiential knowledge into something beneficial to service improvement and development (Cotterell and Morris, 2012).

Despite collaborations between health professionals, managers, service users and other stakeholder groups being encouraged, issues of power and legitimacy are often neglected. Overlooking these challenges led to difficulties enacting user involvement in practice and achieving partnerships with the public. The stroke group were defined by their technical knowledge of stroke services and experiential knowledge of stroke but more attractive to professionals was the group's ability to work in partnership with health professionals and managers armed with knowledge of management processes and stroke services.

As (Freidson, 2001) explains, monopoly, expert authority and credentialism are essential to professionalism for the 'nurturance of specialised knowledge' and the control of occupational work. Users in this case controlled spaces using their authority over other users made possible by their claims to knowledge of the illness but more importantly the skills and knowledge of management processes they brought from their past careers. This is not to say that other users who experienced a

stroke could not be involved, rather this group were seen as more attractive for involvement activities because they readily possessed the skills and education to share and translate their knowledge and experiences of stroke into practice.

This echoes much of the literature (Macdonald, 2003; Crawford et al. 2003) describing those involved as being, 'the same traditional middle-class cross-section of citizenry to represent the interests of all members of the community, rather than to sort through the complex issue of who should represent the public interest' (Church et al., 2002: 17). In contrast to the stroke group, the mental health users did not share the same social backgrounds as the stroke users; although articulate, they did not possess the same educational and financial backgrounds. Users in the group sought to stratify themselves from other 'lay' users who they perceived as being less knowledgeable not about the condition of stroke but about the health system and the management processes such as the stroke pathway. In the same way, the mental health service users sought to stratify themselves from intra group members by claiming expert knowledge. The stratification of 'lay expert' users and 'lay lay' (Elbaz, 1992) users is a point made latterly in Epstein's (1995) work. This work explores this process in more detail, explaining the way in which expert lay users or professional users define 'experts' and 'amateurs' that forms the basis of their credibility claims.

However, in contrast to other groups these users were not characterised by the degree of politicisation, adversarial relations with professionals, and activism as explored in previous studies; e.g. Brown's (1992) study of lay groups acquiring knowledge of

the epidemiology of disease and environmental contaminants; Epstein's (1995, 1996) study of AIDS sufferers acquiring scientific knowledge; and Brown et al.'s (2006) study of challenges to epidemiological knowledge of environmental causes of breast cancer. While the mental health users behaved less like external activists that engage in open conflict with clinical researchers and scientists evident in social movement studies, these users were more like organisational insiders.

The stroke group however although not radical and were able to dictate who they wanted to work with, mainly because they were free from state control, organisational monitoring and because the very knowledge and skills they possessed was what professionals sought. The group was able to exercise its control with health commissioners and professionals of stroke services, where they were not at risk of being marginalised because professionals drew on them for their expertise. These skills gave the group the ability to be able to influence health professionals and managers in service provision. Members of the group shared a common purpose (Barnes et al., 2006) and mobilised themselves as an expert group with knowledge of stroke. Group status provided members with an identity (Barnes and Cotterell, 2012), which is important in an environment where those involved often lack the legitimacy and professional identity amongst health professionals and managers. While users who are involved in managerial controlled involvement activities in top down initiatives often lack the legitimacy and power of user led user groups and social movements, users in these cases sought to define an identity for themselves which saw them as legitimate actors amongst professionals.

In part these users were able to exert control and gain professional status because they possessed a 'body of relatively abstract knowledge' (Macdonald, 1998) which they used to gain social status and rewards in terms of monopolising the user community. The stroke group were able to use this knowledge and form themselves into a group (Macdonald, 1998) and dominate the user community entering into a 'regulative bargain' (Cooper et al., 1998: 8) with health professionals and managers. Where Abbott's (1988) work centres around 'jurisdiction' and Larson's (1977) around the 'professional project' both infer that professions deploy strategies to achieve social and economic rewards, in these cases, users sought social prestige and professional identity. Users' esoteric knowledge and skills, and for the stroke group their previous professional socialisation, enabled them to provide expertise based on knowledge and ability, which other users were unable to do. The stroke group defined the remit of its membership and controlled the professional knowledge of the group, gaining respect and carved for itself jurisdiction (Abbott, 1988: 33).

### *Professional jurisdictions defended*

In contrast to a number of studies (Brown et al., 2006; Epstein 1996), this work shows how credibility claims are derived less from scientific knowledge both acquired and experienced of the illness, and more from claims of expertise around managerial structures and processes. In contrast to Potter's (2010) study who observed how 'wrong' parents with mental illness were not positioned as the 'right' parents, these users were unwell in varying degrees, and so it was not their illness which discredited them from being equal partners in involvement, but rather their lack of management knowledge and expertise. Consistent with Potter (2010) users in

both cases possessed what Potter calls 'alternative expertise'. In contrast however, in the cases in this work, expertise derived from a combination of experiential knowledge, scientific knowledge of the illness and more importantly an understanding of management processes and jargon from users' previous careers and experiences of involvement work.

Although the stroke group did not fall into the category of a typical social movement, it did operate freely outside the political system and identified itself as a collective 'we'. As Morris and Braine (2001: 21) argue '[e]nvironmentalists and antinuclear activists have to build identity, solidarity and consciousness from the ground up'. We observe how the stroke group also sought to build an identity as a professionally led user group and the mental health users as service user consultants. However, Morris and Braine (2001) argue that the process of identity building is in part necessary because activists are not mobilising themselves in the context of their 'personal identities that have an existing subordinate meaning in the social system'. For the stroke users however the skill set and management knowledge from their past careers enabled them to use this as part of building their identity as a professional user group. For this group their initial motivation for forming the group can be seen as more aligned to social movement ideas where there was a dissatisfaction with institutional or social norms (Crossley, 2002), than the mental health service users who saw involvement initially as an opportunity to aid their recovery by being part of a wider user community.

But as Barnes et al. (2006: 196) suggest, while public agencies may define what constitutes legitimate membership by creating limited opportunities for participation,



‘citizens also bring to participation initiatives their own sense of who *should* be involved as well as their own histories and experiences.’ This was evident in both cases where the users in the stroke group defined the remit of membership criteria and where mental health service users who progressed to being consultants described how those who did not understand management processes should not be involved in management activities. Stroke users in the group were from ‘mid to high’ social positions and used their cultural capital as leverage in the health system but also to make claims that other users were not as able as them, where, the education and financial means the group had in itself meant that those users who did not possess such privileges were sidelined.

Similar to ways in which professionals delineate jurisdiction (Abbott 1988; Dent and Whitehead 2001; Freidson 1988, 1994, 2001; Larson 1977, 1979; Nancarrow and Borthwick 2005), members of the stroke group and mental health service users consultants drew upon their education and socialisation to claim positional power and status, which was predicated upon delineating a particular domain of jurisdiction, using their knowledge to position themselves as ‘experts’ compared to ‘amateur’ users (Fournier, 2001); where professional users developed a distinctive identity that enhanced exclusivity and privilege (Currie et al. 2009; Currie et al. 2010; Fournier 2001). The stroke group and service user consultants developed a distinctive identity, defined boundaries and domains to being professional users and gained autonomy (Freidson, 1988) with their ‘own distinctive niche in the system of social stratification’ (Macdonald, 1998) in the user community.

As Freidson (1988) argues, part of the success of a profession is their ability to establish social status and define a social reality in which they can function in so that they are able to use their technical expertise, defining a standard to which it is judged and the degree to which laity can enter into their domains. Similarly, certain service users sought to secure the support of political elites and strategic actors including senior health professionals to further their professional work. Different to ways in which Larson (1977) describes professions' quest to translate 'special knowledge and skills' into 'social and economic rewards', the service users across both the cases, although translating a scarce resource, i.e. the knowledge they brought to involvement work to another, they did so primarily to gain privileges in the user community in the form of social status and prestige rather than economic rewards.

While service user consultants did aspire to eventually move into paid positions either at the Trust or in other organisations, their primary satisfaction came from being recognised as professionals by those professionals they worked with. This desire for social recognition can in part be attributed to the nature of mental illness which is often stigmatised where people with mental health conditions are often marginalised and excluded from mainstream society and perceived as 'mad'. Although the same degree of stigma is not associated with stroke, the condition is long term, as with mental illness in most cases, and it has a debilitating effect, often leaving a person unable to return to how their life was prior to the stroke. In this way, the status of a professional or consultant user provided users with a professional identity, purpose and confidence they lost through the illness.

Rather, than compare their knowledge to that held by professionals, and so shift the balance of power between professionals and users, professional users compared themselves against other users, created a hierarchy of users within the user community. Health professionals and the articulate and expert users, were complicit in such an arrangement as it served both of their interests, in which health professionals continued to define services, but the professional users sought to stratify themselves as an 'elite', a sub-strata, within their own grouping.

Professional stratification of users, akin to stratifications within professions of those delivering the service (Freidson 1984; Harrison and Ahmad 2000; Martin et al., 2009), occurred not just through the efforts of professionals selecting and educating only the articulate and expert user, but also through articulate and expert users' complicity and self-interest. The latter engaged in their own professional projects to maintain professional jurisdiction which involved processes of social exclusion which can restrict 'access to rewards and opportunities to a limited circles of eligibles' (Parkin, 1974). As Lakeman et al. (2007) suggested based on their personal opinions, a certain group of users were making claims to authority based on their knowledge as in professions such as psychiatry. Such is evident in this work and empirically highlights how it was users who not only created this stratification but also sought to maintain it by casting other users as less able and through repeatedly putting themselves forward for involvement activities which also served health professionals' and managers' interests.

As with social movements members of the user led stroke group and service users consultants viewed involvement and the status and identity as a professional user an opportunity to form an identity (Stryker et al., 2000). Members of the stroke group were brought together by their experiences of the illness and health services, and commonalties of their personal identities (Stryker et al., 2000), free from state control the group provided members with a platform to improve stroke services and engender change (Campbell and Oliver, 1996). In doing so, the group strategically positioned itself in a space where the rules of its engagement were defined and controlled by its members rather than the health system and where its political leverage was stronger and had more impact than other groups, which were seen to operate on the margins of the user community.

The position the group held and their attractiveness for involvement activities often with senior health professionals, managers and commissioners, provided them to a large extent with the ability to dictate rather than be dictated to. However, the dark side to the this type of involvement and the mobility of such a user led group was that other groups were marginalised, not only by health professionals and managers, as ordinarily expected but by members of the group. Other groups were perceived as being unable to operate at the same strategic level or as possessing the expert knowledge of services, gained over the years from their work with health professionals. The repeated emphasis from service users, health professional and managers, across both cases, that as well as experiential knowledge of the illness and services, those users who were able to articulate themselves were the most beneficial for involvement activities.

The view that only a professional or consultant user could be involved was reinforced and supported by certain users themselves seeing a repeated pattern of an entrenched socialisation process where the professional user possessed the expert knowledge required for involvement activities at a senior level, while enabling those controlling involvement processes to 'tick the user box'. This contrasts to an extent with existing literature (Bowl 1996; Crawford et al. 2003; Contandriopoulos 2004) where professionals challenge the representative legitimacy of users to retain power and control where: 'Questioning people's representativeness serves to keep power and control with policy-makers and service suppliers; to keep things as they are and maintain the traditional unequal relationship between service recipients and service providers' (Beresford and Campbell, 1994: 318-319). Although health professionals and managers were aware that repeatedly involving certain users was unrepresentative, they did little to change this because it served their own interests and no did not question the representativeness of those they were involved because they were able to understand management processes and work effectively alongside health professionals and managers.

This is not to say that the service user consultants and the user led group were not vocal in their views and opinions and were always in agreement with health professionals and managers, in fact at times and especially the user led group were seen to dominate if not control management meetings around service improvement. Rather, these users were seen as allies and assets in involvement activities because they served as management consultants providing expert advice and knowledge to health professionals and managers who lacked the experiential knowledge of

services but also in some instances the expert knowledge of services and the health system.

Health professionals described how they would turn to professional users because they possessed vast amounts of knowledge of health services from over the years and of the way a range of health departments operated. In similar ways as professions such as law and medicine seek to main power using the knowledge they hold, in the mental health case professional users engaged in jurisdictional disputes and conflicts with other users who they regarded as being less able to maintain their position and space in the user community at the top of the user hierarchy (Abbott, 1988).

### **Outcomes of involvement**

As a result of initial processes of selection and self-selection which created a hierarchy of users who defined themselves not by their laity by their expert knowledge, the outcomes of such processes led to the professional user dominating involvement activities but also unrepresentative involvement and the marginalisation of other users. The users who were seen as 'too much work' were those who could not work effectively with managers and health professionals translating their personal knowledge into something beneficial (Cotterell and Morris 2012). This section discusses ideas around the professional user and how achievable representative user involvement is in practice.

### *The 'professional' user*

The construction of the 'right' user across both cases not something which professionals alone did but which service users sought to do too in order to defend their own jurisdictions. While service users were professionalised through involvement processes in the mental health case, users in the user led group were already seen to be part of a group which had professional status. However, as professionals and service users alike explained what involvement entailed was often so broad and professionals were subject to time and cost restraints that how involvement was enacted was often an interpretation of each actor. For service users, involvement was about fulfilling their democratic rights but also sharing their experiential knowledge of services, and although professionals too thought that users should be involved, this was usually only those users who were seen as able and articulate.

Over time, this looseness of definition led to a socialisation process which saw the professionalisation of a group of mental health service users who were complicit in the marginalisation of those perceived as less able users or 'lay lay' users (Elbaz, 1992). The professionalisation of this group of users was only possible, however, because users' actions and discourses were aligned with existing power structures and the interests of the most established powerful actors; i.e. health professionals and managers. In such a way, any professionalisation project is relational, with interdependence between groups defining how the professionalisation project proceeds. Forming strategic alliances with managers and health professionals (Barnes et al., 2003) and repeated involvement in management activities enabled the

fending off of jurisdictional challenges (Abbott, 1998) posed by other users, and the monopolisation of the user community by a certain group of users and consequently unrepresentative involvement. As such the user led stroke group resonates with Martin's (2009b:6) study of user involvement in pilot projects where, '[u]ser-group members themselves were not mere pawns in this game, being used to legitimate Macmillan's political work but skilful and wilful actors who carved out intricate roles for themselves.'

This construction of the professional user identity, served professional interests where a number of professionals blamed unrepresentative involvement on the repeated self-selection of the 'usual suspects' who were engaging in their own professionalisation project and less on themselves describing how they had tried to involve other lay users. Certain users then constructed the image of the 'lay' user or 'amateur' (Currie et al., 2009) who was unable to effectively work with health professionals as they did, to legitimise their own professional identity. Since there was a certain degree of looseness around what involvement entailed the professional legitimacy and professionalism (to work with health professionals) relied on the construction of the amateur users and the 'invention of amateurism' (Taylor, 1995) to protect jurisdictions. Engaging in their own professional projects, these users sought to 'maintain or enhance their scarcity' (Macdonald, 1998: 10) by claiming other users did not possess the same expert knowledge as they did.

While it is users who usually criticise professionals for using professional jargon creating barriers to user involvement, in this case a number of users who worked with professionals felt that other users should learn boardroom jargon so they can be



involved and work alongside professionals. What involvement entailed differed amongst service users and carers and was often a reflection of their user 'position' (Cotterell and Morris, 2012) and their position in the user hierarchy. By discrediting other less able and articulate users and deeming them unable to be involved, as service users consultants in the mental health case and alike with the user led stroke group did, these professional users were playing 'the user card'; '[i]t takes a highly skilled, politicised user group to exploit this potential. Alliances are crucial. The ground is restless and shifting and the 'game' can be exhausting for anyone with a disability or mental health problem. An independent, radical user group, which can avoid being overmanaged and institutionalised by the agencies, could have much to gain' (Mort et al., 1996: 1140).

Indeed, users in both cases had 'much to gain', the service user consultants in the mental health case who constructed for themselves a professional identity, progressed to the top of the hierarchy of users where they were seen by health professionals and managers as possessing expert knowledge and skills making them easier to be involved. For these users, being involved in management meetings and strategic involvement activities provided them with a professional title of service user consultant and an identity which many users explained they lose with mental health illness. For these users progressing to the role of service user consultant enabled them to possibly then become peer support workers or in other paid positions at the Trust.

Those tasked with engaging users then selected a particular type of user, who tended to be articulate and willing, which inevitably left others marginalised (Church et al. 2002; Contandriopoulos 2004; Harrison and Mort 1998; Hodge 2005). Consequently, expert users were complicit in maintaining professional dominance. As lay users are engaged in less strategic activities, pre-existing inequalities between certain users (e.g. those socially excluded users, or those with significant mental health illness) and those health professionals developing and delivering services (Barnes et al. 2007; Contandriopoulos et al. 2004; Harrison and Mort 1998; Martin 2008b) were reinforced.

While service users sought to construct a professional identity for themselves or the stroke group a collective identity, only at times did they adopt a 'hybrid position' (Kerr et al., 2007) where they wanted to be seen as fighting for the cause amongst other users but in some regards this varied across cases. Mental health users sought to construct individual identities for themselves using the knowledge and skills gained through training and education at the Trust and coupled with management knowledge from their previous careers. Their quest for professional status (Freidson, 1994) was an individual pursuit because they worked individually in service user initiatives where service user consultants stratified themselves from other users and delineated jurisdiction using their knowledge. Members from the stroke group worked more as a collective where each member used their individual knowledge and skill set as well as their patient identity to contribute to the formation and mobilisation of the group and over time constructing it as a professional group which health professionals and managers relied upon.

The characteristics of the professional users, or what was referred to as their professionalism by health professionals and managers; i.e. their ability to understand management processes, and work alongside professionals separated the involved user from the less involved and although resource constraints exacerbated involvement processes, it appeared that these were not the main reason. In this way, these findings contradict a point Beresford and Campbell (1994:320) make: '[w]hen people with learning difficulties, psychiatric system survivors, older people and people with impairments have demanded the right to speak for themselves, they have meant both the right of each individual to express their views and define their needs and also their collective right not to have other groups speaking for them. Not only do we have our own discourses, histories, organisations, policies and demands, but we want these to be fully included in mainstream political, social, economic and cultural debates and developments.'

There is the assumption here that all social movements and involved service users can be involved and 'fully integrated' but given the current constraints in the NHS and the managerially driven environment, the feasibility of involving the masses is questionable especially in strategic activities and at senior management levels. Rather, from these cases it is apparent that different users are involved in different activities and while there is 'a place for every user' there is also the right place for every user where the skill set and knowledge and each user determines which involvement activity they are suitable for and where they can contribute effectively.

Although the service user consultants experienced a process of professionalisation through the training and education provided at the involvement centre and the stroke users' skills and education were largely acquired through their previous professional careers and social backgrounds, both groups of users shared a number of similar qualities which were attractive to those managing involvement activities. In this way, the findings emphasise Church et al.'s (2002: 21) points that consumer representativeness assume a set of characteristics including having 'a strong personality: effective speaker, successful operator, well connected, understands constituents' interviews and pursues them. Having the ability to mobilise a constituency when necessary. Being knowledgeable about the issues.' These characteristics were evident in both groups of users in this work where service user consultants were referred to as the 'loud mouths' who were involved in everything.

However, in these cases there was concern that those users who were supposed to represent the user community in involvement activities, did not feedback what they were doing to the wider user community and were suggested to be unrepresentative and disconnected from current services by service user volunteers. This was similar to Barnes et al.'s (2003:397) findings where forum group members, 'recognized that many of those they claimed to represent would know little or nothing about their activities.' Within the stroke group there was certainly more of an attempt by the group to improve services however because their input in involvement and participatory activities with health professionals and managers was based on a reflection of only their experiences of services and their opinions and views, which were affected by their social backgrounds that being were educated, white and

middle class, health professionals and managers questioned about their representativeness and knowledge of current services. It became apparent that over time these users became static and tended '[...] to lose touch with the values of the average citizen.' (Glaser and Bryan, 2003: 28).

The socialisation processes in both cases, including processes of selection and self-selection that gave rise to a hierarchy of users and the construction of a professional identity for a certain cadre of users which saw them stratifying themselves from other less able users led to unrepresentative involvement. As Church et al. (2002: 21-22) explain 'Without either the capacity to mobilise local constituents or to be viewed as legitimate by those constituents and other major stake-holders, the likelihood of the average citizen playing a meaningful role in decision-making on local boards is limited. This presents a dilemma because those individuals most likely to possess the significant resources to effectively engage in these activities tend to come from a narrow (higher middle-class) segment of the community.' This was reflected in the user led stroke group where all the members of the group had previous very senior management careers, were educated to a high level and had the financial resources to form and run the group (Ryfe 2005; Wright 2013). While the service user consultants may not have been from quite the same middle class backgrounds as the stroke users, they did possess knowledge of management processes, were articulate and able to work as equals alongside health professionals and managers.

Essentially then, both sets of users possessed a form of expert or specialist knowledge as well as experiential knowledge of services and additional skills, which they used to stratify themselves from other users delineating jurisdiction and claiming professional status. As with professions (Macdonald, 1988), users' quest was one of being leaders in the user community and to an extent monopolising it using their expertise achieving status in the user community, where those perceived as ineligible both by professional users and health professionals and managers, were excluded from strategic and management activities and denied the status and access to knowledge associated with it. This notion of being a 'professional' or 'consultant' user was an identity and status that was achieved over time through training, experience and users' knowledge of management processes acquired from their past careers and involvement activities. This construction of the 'right' or 'eligible' users was in theory open to all users but one which only certain users achieved.

Whether the term 'professional' is entirely reflective of what this group of users were is debateable, but these users did possess many of the characteristics and act in many ways similar to that of professions, displaying professionalism, possessing expert knowledge and closing off markets by casting other users as amateurs, in order to achieve social status and prestige. As a number of interviewees pointed out however it was often the most intelligent, able and articulate users who progressed to the top of the user hierarchy and assumed what was perceived as more important user positions. While a range of users were involved, these were in different activities, that is, the more able users were involved in more demanding activities, which were usually strategic management decisions and on senior levels, whereas

less able users were involved in gardening and reading groups. The issues here was not only one of a representative deficit but also that these processes contributed to the stratification of users and the exclusion of a range of user opinions at the decision making level and thus maintaining the status quo (Beresford and Campbell 1994; Bowl 1996).

### ***Representative involvement achieved?***

As discussed above, processes of involvement including the selection of those viewed as the 'right' users by professionals controlling involvement process and the self-selection of those wanting to be involved led to pattern where those users who were seen to not have the skill and knowledge for involvement were marginalised not only by professionals but more by those users with expert knowledge. Service user representativeness was seen as unrealistic goal amongst health professionals who questioned how everyone could be involved and where involving service user consultants was easier because of their skills despite them being 'out of touch' with current services. While it is experiential knowledge of the health condition or illness which is seen as valuable to involvement processes, what emerged was that it was not only this knowledge or experiences of health services that was sought by professionals but more the knowledge of management processes and the ability of certain users to work alongside professionals. Thus these 'other skills' (Potter, 2010) and the ability of certain users to "turn their experiential knowledge into something else: a translation process where their knowledge is transformed, in their own mind, and in discussion with others [...], into something generalisable: something that be

acted upon” (Cotterell and Morris 2012, pg. 68) were crucial to involvement activities.

Although all of the service users and carers who came to the involvement centre and the Trust were involved in different activities, the capacity of their involvement and the level which they were involved at differed. If services are to be improved or developed through user involvement, ensuring that involvement is representative in those activities is important. Because of the different capabilities of users and certain users putting themselves forward for activities, rather than representative involvement, a nucleus of users existed who were often repeatedly involved. Although service user consultants did not claim to be representative of the user community they did describe how they represented the ideas of a number of users yet a number of users explained how they were unsure what user consultants were actually doing in management meetings because they did not feedback results to the wider user community and knew little of what others were doing (Barnes et al., 2003).

Involvement for the Trust centred around the involvement centre, providing users with a place where they could share their experiences of mental health and the services with other users and professionals. As part of this, service users were seen as integral to improving mental health services, although many of these activities at the involvement centre were in the form of feedback forums, being part of interview panels and organising events for mental health awareness. As part of this users could undergo training and education such as with literacy, numeracy and computer skills,



these processes of involvement enabled certain users to be able to work across the Trust in more strategic activities such as on management boards, service development initiatives and alongside academics. What this led to however was what Glaser and Bryan (2003: 28) describe as 'a static pool of citizen participants [that] tends to lose touch with the values of the average citizen'.

While ordinarily professionals undermine the legitimacy of those involved by claiming they are not representative of the wider user community, in these cases although professionals admitted the users were unrepresentative they still involved them because they had the skills and knowledge desirable for involvement activities. In contrast to other work (cf. Martin and Finn, 2011) where users were constructed as lay patients rather than knowledgeable partners, in these cases health professionals and managers saw the valuable contribution certain users could make, with their experiential knowledge of the illness and health services, and their expert knowledge of management processes and skills.

Health professionals, managers and users alike constructed what they thought user involvement should entail which fit neatly into their work patterns. This contrasts to some extent with existing studies (Bowl 1996; Contandriopoulos 2004; Crawford et al. 2003) and the view that professionals challenge the representative legitimacy of users to retain control and power in user involvement. As Martin (2008b) notes, in his work on service user involvement in cancer-genetics, user representativeness are only important if they threaten or challenge the status quo because their views and technocratic contribution (Martin 2008b:10) align with those of health professionals

and managers. But because those involved did not seek to challenge health professionals or even if they did, such as in the stroke case, they did so in a way which was beneficial for the health services, their legitimacy was unquestioned.

Representativeness then and the way in which involvement is enacted in practice may always be subjected to the interpretations of not only professionals but also of users because of the lack of rigidity around what involvement entails. Not only is the form involvement is supposed to take and the various user roles left to the interpretations of those managing involvement processes but various democratic, ethical and professional justifications are also intertwined into these policies making its enactment more complex than envisaged. Thus any form of representative involvement or representation of the public in public involvement initiatives will be faced with professional and user struggles over what constitutes credible knowledge and how this should be used to improve services. What we observe however, is how not only professionals play the 'user card' (Harrison and Mort, 1998) as a means of legitimising their own interests (Contandriopoulos et al. 2004; Harrison and Mort 1998; Rowe and Shepherd 2002) but how certain users too are carving out jurisdiction using their expert knowledge leading to a hierarchy of users (Lakeman et al., 2007) where users alike are marginalising other users who they perceive as less able.

Over time then the struggles between professionals and users have slowly started to shift in cases such as this study where certain users are becoming allies of professionals. While they may still be pursuing the needs of the wider user

community to some extent, their quest for professional status creates a repeated pattern of the absent voice. The problem with these situations is that over time professional users or 'celebrity' or 'corporate' users will use their knowledge to make claims to power causing rifts in the user community and the stratification evident in professions such as psychiatry will be mirrored amongst users (Lakeman et al., 2007). Therefore there cannot be the assumption that involved users are egalitarian and representing the masses with no agenda of their own. While existing studies discuss the power struggles between users and professionals, issues around representativeness and lay expertise, this work makes contributions in these areas but more nuanced are the findings on the processes of the stratification of users which leads to unrepresentative user involvement.

In this way, the findings around the ambiguity of users' roles and user representativeness emphasise Barnes et al.'s (2003: 397-398) point that, 'in particular, the importance of the micro processes through which official and lay discourses of the notion of 'representation' and legitimate participation are being negotiated suggests that the analysis of official discourse alone is insufficient to understand how 'the public is constituted for public participation.' and where there were differences 'across as well as within the different deliberative forums [...] highlighting the selectivity applied by both officials *and* citizens in constituting legitimate membership in different circumstances'. This highlights that there is significant ambiguity about the ways in which the public are involved both where involvement is enacted within an organisation as a response to complex policy rationales and also with those user led groups which are free from state control.

Involvement processes then become a 'complex justificatory negotiation' (Martin, 2008b) between the different groups involved where issues of power, legitimacy and knowledge become entrenched in the socialisation process occurring.

## **Conclusion**

In examining processes of user involvement across two cases this study described how users in the mental health case went through a process of professionalisation while the stroke users used their skills and knowledge from their previous careers to construct a professional identity and delineate jurisdiction while casting other users as amateurs. Through processes of selection by those managing involvement processes and self-selection by those users who wanted to be involved and who were known to health professionals and managers a hierarchy of users (Lakeman et al., 2007) emerged where certain users were deemed more capable and articulate than others and therefore more suitable for involvement at management and board levels. Although a number of processes during involvement differed, users across both cases sought to construct a professional identity for themselves by delineating a distinct body of expert knowledge.

While the boundaries between professionals and users are already entrenched with power struggles, notions of legitimacy and credibility of knowledge and authority (Barnes 1999; Beresford and Branfield 2006), these were further exacerbated by professional users creating their own inclusion and exclusion criteria of who they deemed as credible to be involved alongside health professionals and managers. We

observe how a number of users deployed various strategies to justify their claims that they were credible users to be involved. While their experiential knowledge of services and the illness was seen as a reason for their involvement, it was in fact their ability and professionalism to work professionally with health professionals and managers and their expert knowledge of health services and management processes.

Service user consultants gained their credibility through undergoing training and education at the involvement centre but also from the skills they already had from their previous careers and lives prior to becoming mentally unwell. In essence, involvement was a function of users' wellness leading to unrepresentativeness based on illness, as extant work suggests. However in addition to this, even where certain users were well, managerial expertise and experiences allowed them to have a greater level of involvement rather than possession of clinical knowledge of the illness or condition, their illness in large parts simply provided them with legitimacy to be part of the involvement centre. The processes these users went through saw their professionalisation where they adopted a professional identity and a title of service user consultant, one seen as more superior than service user volunteer. Demand for their repeated involvement at board level and in management activities further defined their role of service user consultant where they stratified themselves from other users in the user community.

Although users from the stroke group did not undergo a process of professionalisation as such, they used their experiential knowledge, expert knowledge of the health system and their 'other skills' (Potter, 2010) of communication and professionalism gaining privilege to be involved in senior

management activities and social status (Macdonald, 1998). The label of professional user and service user consultant was seen as a much sought after identity and as with professions such as law and medicine enhanced these users' exclusivity and status (Currie et al., 2009). Since professional identity is open to contest, status and legitimacy have to be achieved and reproduced in relation to other group, individuals and professions (Currie et al., 2009). Users sought to do this by casting other less able, educated and articulate users as amateurs or ineligible (Currie et al., 2009) unable to carry out the same specialist that only 'professional' (Fournier, 2001) users could carry out.

Over time this saw a hierarchy of users emerge in the mental health case, with the role service user consultant seen as the most exclusive, and amongst the stroke users the collective professional identity and work of the group seen as being unable to be replicated by other groups. As with professions such as law and medicine, these users carved out specialised bodies of knowledge to fend off jurisdictional challenges (Abbott, 1988) enabling them to render privileges of repeated involvement creating a sense of importance and self-worth, the continued status of a 'professional' user, and monopolisation (Freidson, 1970) in involvement activities. This served both their own interests and those managing involvement processes but ultimately led to unrepresentative user involvement and the marginalisation of the less able and articulate user. There was certainly an element of wellness attached to which users were seen as appropriate to involve. Therefore it was usually the most vulnerable that were not involved because they were seen as not possessing the skills and ability to be included, despite maybe possessing the required knowledge. This

work is not concluding that certain users are becoming a new occupational group as such, but rather that they are adopting many of the strategies professions use to claim professional and status.

Emergent from the data was that it was not only the experiential knowledge of users that was valuable to professionals but also the ability of users to interact with professionals and understand management process, characteristics health professionals and managers referred to as users being 'professional' and demonstrating 'professionalism'. The use of the terms professional and professionalism by those managing involvement initiatives often were used to refer to users who had not only become more knowledge about the illness (Haug, 1974) but also their discourse of professionalism (Evetts, 2003; Fournier, 1999) including their values and identities (Aldridge and Evetts, 2003), mannerisms (Swick, 2000) and ability to deal with complex knowledge based tasks and uncertainty that provided them with power (Hickson et al., 1971), autonomy and self-regulation (Harrison and McDonald, 2008), rather than the users being a professional group per se such as professional groups in medicine in law where knowledge is certified and regulated by external institutions.

Professional service users not only displayed professional behaviour but also engaged in professionalisation strategies such as casting others users as too lay or unable to operate at the level they did. This fending off encroachment from those they perceived as being less able users who did not possess the expert body of knowledge required for involvement activities at a senior level such as on

management boards. Further, the discourse between service users, health professionals and managers took place within an ideology of managerialism. This ideology legitimised managers' and health professionals' claims to professional status and encouraged the belief and value system that privileged the role of managers in involvement initiatives and those professional service users who operated within this framework.



## **CHAPTER 8: CONCLUSION**

### **Introduction**

This concluding chapter draws together the research findings, summarises the theoretical contributions and reflects on the practical implications for user involvement policy and practice. The aim of this study was to examine the user involvement process by answering the following research questions:

R1. What are the processes leading to the stratification of users?

R2. What are the outcomes of involvement processes?

To answer these questions I examined user involvement processes across two cases bringing together the empirical analysis, theories from existing studies on user involvement through the lens of the sociology of professions literature to answer the research questions.

Health professionals and managers are increasingly faced with the task of involving service users in service improvement and development as well as research, often with little financial resources and time, they find themselves at a crossroad to involve a representative user but also a user who is articulate, able to understand involvement activities and the health system. Faced with these challenges, and a need to meet management targets, professionals often select those users who are known to them and those users who put themselves forward for involvement. A plethora of studies on user involvement exist but little research existed on why users put themselves

forward for involvement and the tensions within the user community. Drawing on two cases of user involvement, what I hope I have demonstrated is a more transparent understanding of involvement processes and the paradoxes that arise during such processes.

This final chapter considers the findings in the context of existing work, highlighting the contribution I hope I have made. Considering the findings from this work and the conclusions made, the implications for policy and user involvement in practice are discussed as well as the transferability of the findings. Finally, the limitations of the study are noted and avenues for future research are suggested.

### **Theoretical contribution**

Following the introduction, the second chapter set out to explore policies and the history of user involvement, as well as review the extant literature. From this review, two main themes emerged which served as a platform for this work. One theme centred on what constitutes lay expertise and what skills and knowledge service users brought to involvement activities (cf. Cotterell and Morris 2012; Potter 2010; Prior 2003). While a number of studies suggest that the knowledge possessed by lay people is distinct and can make productive contributions to health service development and delivery (Epstein 1995; Lambert and Rose 1996; Martin 2008, 2008b; Nettleton and Burrows 2003; Whelan 2007; Ziebland 2004) it remained unclear what knowledge and skills were necessary for involvement and what knowledge viewed as credible by professionals.

A second theme was user representativeness and the paradox which saw professionals employing those users who were seen as a 'safe pair of hands' (Hogg 1999, p. 100) and were known to the organisation. Notions of the 'right' user who was a 'safe pair of hands' (Hogg 1999, p. 100) where certain publics possessed expert knowledge or 'other skills' (Potter 2010; Thompson et al. 2012) led to a paradox where those involved would inevitably be limited to certain users, who were able to understand and work with professionals (Daykin et al. 2004; Learmonth et al., 2009) and who were often well educated and middle class (Church et al. 2002; cf. Epstein 1995,1996 HIV/AIDS activists). The medical profession and health settings are awash with power struggles over jurisdiction and claims over the credibility of knowledge. The integration of service users and the public into such spaces has created struggles around representational legitimacy and competing claims around what constitutes credible knowledge by those managing involvement processes (Barnes 1999; Beresford and Branfield 2006; Beresford and Campbell 1994; Hodge 2005).

A key study which informed this work was Lakeman et al. (2007), who suggest certain users claim authority and knowledge such as in the profession of psychiatry which has led to a hierarchy of users. However, this study did not describe the processes behind this stratification and the work was based on the authors' personal views and experiences as in psychiatry. The literature and preliminary field work suggested that while professionals select and involve the 'right' user for further their own interests, there was no empirical work to suggest if users also benefit from

processes of selection and self-selection, and if a hierarchy did exist as Lakeman et al. (2007) suggest, there were questions around how and why this emerged.

Mindful of the existing competing bodies of knowledge amongst service users, managers and health professionals, and the emergence of a proposed hierarchy of users (Lakeman et al., 2007), I examined the involvement processes and the stratification of users, through the lens of the sociology of profession. I hope that this highlighted that certain service users in similar ways to professions, carve out an expert body of knowledge and use this to delineate jurisdiction, professional identity and power (Larson, 1977) engaging in a 'collective mobility project' to advance their social position and status.

The outcomes of involvement processes led to a hierarchy of service users where 'professional' users in both cases, were seen to dominate the user community and involvement activities. Although these users did not possess the same degree of political activism as in other cases (Epstein 1995, 1996; Lambert and Rose 1996; Nettleton and Burrows 2003; Whelan 2007; Ziebland 2004) there were similarities, such as users' acquisition of a form of knowledge to gain credibility amongst health professional and managers. In doing so, a certain group of service users sought to stratify themselves from other users (Lakeman et al. 2007; Thompson et al. 2012) assuming a sort of 'hybrid position' (Kerr et al., 2007) by casting other less able and articulate users as amateurs or ineligible (Fournier 2001; Taylor 1995).

Rather than making credibility claims using their experimental knowledge of services and the illness or their scientific knowledge (cf. Epstein 1995; Brown 2003) they did so with their knowledge of management processes, the health system and their 'other skills' (Potter 2010; Thompson 2012). This included their communication skills, ability to articulate and translate their experiential knowledge into a useful form and their professional discourse, the latter serving as an 'effective mechanism of social control' (Evetts, 2003b) amongst those they worked with. While this was not for financial gains, although service user consultants did aspire to move into paid positions at the Trust, it was to construct a professional user identity for themselves enhancing their exclusivity and status in the user community. By closing off 'markets' and opportunities for other users, by constructing the image that others were amateurs thus legitimatising their professional identity (Taylor, 1995), this cadre of users carved out a distinct body of expert knowledge. This enabled them to engage in their own professional projects (Larson, 1997), bound by exclusivity and status, while simultaneously serving the interests of those managing involvement processes, but leading ultimately to stratification within the user community and unrepresentative service user involvement.

### **Implications for practice and policy**

A number of implications arise for practice and policy from this work. The lack of clarity about how user involvement should be implemented meant that professionals would seek users who were trained, articulate and who understood what was required of them in involvement initiatives. While a number of professionals had

tried to involve 'lay' users they found that these users brought their own agendas to meetings and did not understand management routines and jargon, a point noted in previous studies. While the aim of involvement was to capture lay opinions and experiences of health provision, it was users' knowledge of management processes and ability to interact with health professionals and managers which was most attractive. These characteristics differentiated the in-group from the out-group, the service user consultants from the service user volunteers creating 'layers' of users and ultimately leading to unrepresentative user involvement.

These entrenched socialisation processes and the emergence of the professional user and unrepresentative user involvement, warrants questions on notions of representativeness and its practicality in practice. While there are expectations that all users, or at least a range of users should be involved at all levels of the organisation, in practice different users were suitable for different activities, with the most articulate users being involved in senior management meetings and at strategic levels. Policies around user involvement need to consider the practicality of involvement in practice and the wider social tensions which exist not only between health professionals, managers and users but also increasingly within the user community.

There is long history of stigma attached to mental health illness, where the label or social identity attached to it has negative consequences on the individual (Scheff, 1966) and usually remains with the person. For many service users, this has been a barrier to their involvement because they have been seen as 'mad' or too mentally

unwell to be involved. Health professionals and managers may use this as an excuse for not involving those users who they perceive as being less able and articulate and because of this involve a service user who is trained and known to them. There is not the same stigma attached to stroke as mental health but the physical and mental impact stroke has on survivors affects the capacity of their involvement. In this case, there was a sense that because the stroke survivors were retired professionals who were financially independent, this provided them with the ability and means to be more mobile and received better treatment for their condition, at times privately. The health professionals in this case felt that this provided the group with an advantage of those patients from lower socio-economic backgrounds.

Users in both of these cases had no qualms about being unrepresentative and especially in the mental health case felt that their role was not about representing the user community but more about an individual job to service a almost a management consultant. The stroke group did make an effort to represent the views of the wider stroke survivor community and improve services but still neglected to actively involve other users in their group who they regarded as less able therefore promoting the involvement of the 'elite' user that mirrored the backgrounds of those users in their group. Policy around user involvement and patient and public involvement then needs to consider the wider implications of policy in practice, while not only accounting for the practical challenges of user involvement but also how the associated illness, both mental and physical, have on the ability to enact involvement. Policy around representative user involvement requires clarity about

who is representative and the practicalities of whether representative involvement is both realistic and necessary.

A number of upheavals have occurred, including Clinical Commissioning Groups (CCGs) coming into force and the breakdown of PCTs. The DoH has outlined the health and care system from April 2013 explaining how the different statutory bodies in the system will work together in the interests of patients and communities. As part of this, the public are to be given more freedom of choice and involvement in service planning where Healthwatch organisations will provide patients and communities with a voice in decision making and experiences that affect them. How these plans and policies are enacted in practice and whether existing user groups are involved or new and a wider range of publics are drawn upon is yet to be seen.

### **Limitations of study and future research**

I hope in this work to have demonstrated the processes behind the stratification of users, the construction of a professional user identity and notion around user representativeness. Further insights are required to fully understand the involvement processes and the micro processes taking place. Despite interviewing a number of professionalised service user consultants in the mental health case and professional users from the stroke group, the latter had no immediate point of comparison. That is, there was no other user led group who were not 'professional' users to compare how they were included, or not, in involvement activities. As such larger scale



research and even international comparatives of involvement would be fruitful and would help to further validate the findings.

While parts from the sociology of professions literature can be drawn on and applied to this work on the professionalisation of service users and their 'professional' status, in terms of their skills and education they bring to involvement work, there are obvious limitations. First, Weber (1978) states, the knowledge in question is that which is certified and credentialled through established institutions and regularity organisations and it is this that provides occupations with social closure and enhances its social status in society. The knowledge which service users bring to service improvement and development is their experiential knowledge of the illness which is neither credentialled or certified. As well as their experiential knowledge of the illness, service users bring their knowledge of managerial processes coupled with their previous education and occupational work experience. Arguably this later form of knowledge is to some extent certified and credentialled. As will be explained, the users in the mental health case undergo training and education within the Trust, which although not credentialled by a state institution, it within the realms of the user community certified and rigorous. The users in the stroke group are all from educated, middle class background having worked in senior management positions.

Second, and linked to notions of expert knowledge, it can be argued that users do not bring expert knowledge to involvement as such but they simply bring a different perspective, one that health professionals and managers do not have and one which is required by policymakers. However, it is this very knowledge that makes certain

users 'experts' by experience coupled with their ability or professionalism to work alongside health professionals.

Third, it is important to note that I am not concluding that the users in this work are a new professional group or are professionals as such, rather that the status and identity of professional users, whether this is self-given or given by the health organisation, grants them similar privileges to professions. In addition, the ways in which they use their expert knowledge, within the realms of the user community and amongst health professionals and managers, to sideline other users casting them as ineligible and enhance their own self-image and 'career' are comparable to typical professions.

Fourth, although the service users in both cases were not managerialised there were degrees of managerial control and ideologies from the health professionals and managers involved with the service users in both cases. Specifically in the Mental Health Trust, the structures in place to promote and develop service user involvement were enforced by a top down management system and enacted by managers in the Involvement centre who were managing service user involvement activities. Without these management values and practices, the professionalisation processes the service users underwent would arguably not have taken place. In comparison, the service users in the stroke case were subject to less management control by the managers and health professionals they worked alongside. This was because the stroke group were an autonomous user led group free from state influence and therefore control. Still, to an extent there was an element of managerial

influence but the stroke survivors were able to dictate how the group was run and form their own identity and ideologies.

Certainly in both cases, the service users sought to create a market monopoly by using their expert knowledge, acquired both during involvement processes and that from their previous occupations, to delineate jurisdiction stopping other encroaching on their territory. In doing so the service users in both cases were able to enjoy the status the title of 'professional' had that played a large part in their identity reconstruction.

The methods used to answer the research questions, while clearly having their strengths also have a number of limitations. The number of interviewees could have been increased to further incorporate a wider range of service users in both cases. However, the particularities of the cases, and the mental state of a number of potential interviewees in the mental health case, meant that I could not interview as many people as I had been intended to gain a richer breadth of data. Simply being present however in meetings and the tacit knowledge acquired from being there were crucial to my understanding of the cases and informed the analysis that followed. While I attended a number of meetings in both cases, there were certain meetings I could not go to either because I was not provided with the opportunity to or because I made the decision that these would not add substantial insights to the data from the interviews.

In terms of the generalisability and transferability of the results, a number of points are noted.

While the two cases offer different insights into processes of user involvement, the particularities of the cases themselves possess a number of specific characteristics that informed the way involvement was enacted and which may differ in other settings. The mental health case saw an involvement centre internal to the Trust, where dedicated funds were allocated for the training and education of service users who then moved around across the Trust and were involved in a number of activities. The organisational configuration of the involvement centre is important to this case. It is a managerialised setting where those users involved at a senior level adopted management behaviours, than perhaps other less rigid top down user involvement settings or user led groups such as the stroke group.

While other Trusts have policies in place to involve service users, this specific Trust was unique to an extent and one of only a small number in England with having an involvement centre specifically designed to respond to policies on user involvement. Exploration of user involvement processes within other Trusts, healthcare organisations and in different health settings, where a designated space for users did not exist and was less organised would be useful to understand whether users are professionalised in the same way.

There were obvious limitations to the stroke case where only those stroke users in the group were interviewed. Although there were a couple of other potential users in the group they were too unwell to be interviewed and given the nature of the illness and that of users in the mental health case this was expected. The collective professional identity of the group enabled their repeated involvement alongside

health professionals and background and as a group they agreed that other users and groups would be unable to be effectively involved in the same way. With the service user consultants there were tensions *within* the user community whereas the user led group worked more as a collective.

Despite the united front of the stroke group, I later suspected there were tensions between the users in the group and the founder of the group. Such tensions are evident in social movements where although the groups or movements are bound by their solidarity to fight for the 'cause' as we observe in a number of studies (Epstein 1995; Lambert and Rose 1996; Nettleton and Burrows 2003; Whelan 2007; Ziebland 2004) tensions emerged where those leading the groups were to have lost touch with the group and become 'lay expert' (Elbaz, 1992). Such processes would be interesting to study in user groups where a collective identity is formed but which may conflict with a user's person or role identity. Both of these cases drew on long term illness and so studies examining the professionalisation of users in different health settings, where the severity and length of the illness differs, and whether the reconstruction of professional identity through user involvement activities exists would be useful.

While based on two cases with their own specific particularities, certain points are perhaps generalisable to the wider arena of involvement initiatives in health provision. As already noted in previous studies, there remains a disjoint between policy around involvement and user involvement in practice where roles, identities, power and negotiations between actors at various levels are ongoing. The research

highlights another dimension to the complexities of user involvement in practice, that is, the stratification of users and the marginalisation of users from involvement activities not only by health professionals and managers but now by users themselves. The lack of clear definition around user involvement and representativeness, created a space where certain users contributed in defining the identity of the 'professional' user which was supported by health professionals and managers. I hope to have highlighted that the professionalisation and stratification of users, adds another layer to the existing complex user involvement processes, where such socialisation processes *within* the user community are important to consider in practice and policy.

## References

- Abbott, A. 1988. *The Systems of Professions*. Chicago, IL: University of Chicago Press.
- Abbott, A. 1995. Boundaries of social work or social work of boundaries? *Social Service Review*, 69(4): 547-562.
- Abelson, J., Forest, P.-G., Eyles, J., Smith, P., Martin, E. & Gauvin, F.P. 2003. Deliberations about deliberative methods: issues in the design & evaluation of public participation processes. *Social Science and Medicine*, 57(2): 239-251.
- Abramson, J. 1994. *We, the Jury*. New York: Basic Books.
- Ackroyd, S. & Fleetwood, S. 2000. *Realist perspectives on organization and management*. London: Routledge.
- Ackroyd, S. 1996. Organization contra organizations: Professions and organizational change in the United Kingdom. *Organization Studies*, 17(4): 599-621.
- Aldridge, M. & Evetts, J. 2003. Rethinking the concept of professionalism: the case of journalism. *The British Journal of Sociology*, 54(4): 547-564.
- Allsop, J. & Mulcahy, L. 1996. *Regulating medical work: formal and informal controls*. Buckingham: Open University.
- Altman, D. 1994. *Power and Community: Organizational and Cultural Responses to AIDS*. London: Taylor and Francis.
- Anderson, E., Shepherd, M. & Salisbury, C. 2006. 'Taking off the suit': Engaging the community in primary health care decision-making. *Health Expectations*, 9: 70-80.
- Anderson, W. & Gillam, S. 2001. The elusive NHS consumer: 1948 to the NHS Plan. *Economic Affairs*, 21(4): 14-18.
- Arnstein, S. 1969. A ladder of citizen participation. *Journal of the American Institute of Planners*, 35(4): 216-224.
- Barnes, M. & Bowl, R. 2001. *Taking over the asylum: Empowerment and mental health*. London: Palgrave.
- Barnes, M. & Cotterell, P. 2012. *Critical perspectives on user involvement*. Bristol: The Policy Press.
- Barnes, M. & Cotterell, P. 2012. Introduction: user movements. In Barnes, M. & Cotterell, P. 2012. *Critical perspectives on user involvement*. Bristol: The Policy Press, pp. 1-5.
- Barnes, M. 1999. Users as citizens: collective action and the local governance of welfare. *Social Policy & Administration*, 33(1): 73-90.
- Barnes, M. 2002. Bringing difference into deliberation: disabled people, survivors and local governance. *Policy and Politics*. 30 (2):245-259.
- Barnes, M., Knops, A., Newman, J. & Sullivan, H. 2004a. The micro-politics of deliberation: case studies in public participation. *Contemporary Politics*, 10(2): 93-110.
- Barnes, M., Newman, J. & Sullivan, H. 2004b. Power, participation, and political renewal: theoretical perspectives on public participation under New Labour in Britain. *Social Politics*. 11(2): 267-79.
- Barnes, M., Newman, J. & Sullivan, H. 2006. Discursive arenas: deliberation and the constitution of identity in public participation at local level. *Social Movement Studies*, 5(3):193-207.

- Barnes, M., Newman, J., Knops, A. & Sullivan, H. 2003. Constituting 'the public' in public participation. *Public Administration*, 81(2): 379-399.
- Barnes, M., Newman, J. & Sullivan, H. 2007. *Power, participation and political renewal: case studies in public participation*. Bristol Policy: Press.
- Bate, P. 2000. Changing the culture of a hospital: From hierarchy to networked community. *Public Administration*, 78(3): 485-512.
- Benton, T. & Craib, I. 2001. *Philosophy of social science: The philosophical foundations of social thought*. Hampshire: Palgrave Macmillan.
- Beresford, P. 2001. Participation and social policy: transformation, liberation or regulation? *Social Policy Review*, 14: 265-290.
- Beresford, P. 2005. 'Service User': Regressive or liberatory terminology? *Disability and Society*, 20(4): 469-477.
- Beresford, P. & Branfield, F. 2006. Developing inclusive partnerships: user-defined outcomes, networking and knowledge - a case study. *Health and Social Care in the Community*, 14(5): 436-444.
- Beresford, P. & Campbell, J. 1994. Disabled people, service users, user involvement and representation. *Disability and Society* 9(3): 315-25.
- Bhaskar, R. 1989. *The possibility of naturalism*. Hemel Hempstead: Harvester Wheatsheaf.
- Blaauwbroek, H. 2002. Patient organizations and patients' rights. In: Van Rooij, E., Kodener, L., Rijsemus, T., Schrijvers, G., *Health and healthcare in The Netherlands*. Maarssen: Elsevier Gezondheidszorg; pp. 323-337.
- Boardman, J., Currie, A., Killaspy, H. & Mezey, G. 2010. *Social Inclusion and Mental Health*. London: Royal College of Psychiatrists Publications.
- Bowl, R. 1996. Legislating for user involvement in the United Kingdom: mental health services and the NHS and Community Care Act 1990. *International Journal of Social Psychiatry*, 42(3):165-180.
- Branfield, F. & Beresford, P. 2010. *Count us in! Involving everyone in health and social care research: Report of a service user workshop*. Shaping our Lives, London.
- Broadbent, J., Dietrich, M. & Roberts, J. 1997. *The End of Professions? The Restructuring of Professional Work*. London: Routledge.
- Brown, D. 1998. Narrative, politics and legitimacy in an IT implementation. *Journal of Management Studies*, 35(1): 35-58.
- Brown, I. 2001. Organizational values in general practice and public involvement: case studies in an urban district. *Health and Social Care in the Community*, 9(3): 159-167.
- Brown, P. 1992. Popular Epidemiology and Toxic Waste Contamination: Lay and Professional Ways of Knowing. *Journal of Health and Social Behavior*, 33:267-281.
- Brown, P., McCormick, S., Mayer, B., Zavetoski, S., Morello-Frosch, R., Altman, R. G. & Senier, L. 2006. A lab of our own: environmental causation of breast cancer and challenges to the dominant epidemiological paradigm. *Science, Technology and Human Values*, 31(5): 499-536.
- Brown, P. & Zavestoski S. 2004. Social movements in health: an introduction. *Social of Health and Illness*, 26(6): 679-694.
- Brownlea, A. 1987. Participation: myths, realities and prognosis. *Social Science & Medicine*, 25(6): 605-614.



- Bryman, A. 1989. *Research methods and organisation studies*. London: Routledge.
- Buckland, S., Hayes, H., Ostrer, C., Royle, J., Steel, R., Terpey, M., Walton, J. & Yeeles, P. 2007. *Public Information Pack (PIP): How to get actively involved in NHS, public health and social care research*. INVOLVE.
- Calnan, M. & Williams, S. 1995. Challenges to professional autonomy in the United Kingdom? The perceptions of GPs. *International Journal of Health Studies*, 25(2): 219-241.
- Cameron, D. 2009. *David Cameron's Speech - The Big Society*, November 10<sup>th</sup> 2009.
- Campbell, J. & Oliver, M. 1996. *Disability politics. Understanding our past, changing our future*. London: Routledge.
- Campbell, K. 2005. Theorizing the authentic: identity, engagement, and public space. *Administration and Society*, 36(6): 688-705.
- Campbell, P. 1996. The history of the user movement in the United Kingdom. In Heller, T., Reynolds, J., Gomm, R. Muston, R. & Pattison, S. (eds.) *Mental Health Matters*. pp. 218-225. Basingstoke: Macmillan.
- Campbell, P. 2001. The role of users in psychiatric services in service development – influence not power. *Psychiatric Bulletin*, 25: 87–88.
- Carr, S. 2004. *Has service user participation made a difference to social care services*. London: Social Care Institute for Excellence.
- Carr, S. 2007. Participation, power, conflict and change: Theorizing dynamics of service user participation in the social care system of England and Wales. *Critical Social Policy*, 27(2): 266-276.
- Chandler, D. 2001. Active citizens and the therapeutic state: the role of democratic participation in local government reform. *Policy and Politics*, 29(1): 3-14.
- Charles, C. & DeMaio, S. 1993. Lay participation in health care decision making: A conceptual framework. *Journal of Health Politics*, 18(4): 881–903.
- Church, J., Saunders, D., Wanke, M., Pong, R., Spooner, C. & Dorgan, M. 2002. Citizen participation in health decision-making: Past experience and future prospects. *Journal of Public Health Policy*, 23(1): 12-32.
- Clarke, J. 2005. New Labour's citizens: activated, empowered, responsabilized, abandoned? *Critical Social Policy*, 25(4): 227-463.
- Coburn, D., & Willis, E. 2000. The medical profession: knowledge, power and autonomy. In Albrecht, G., Fitzpatrick, R. & Scrimshaw, S. (eds) *Handbook of social studies in health and medicine*. London: Sage. pp.377-393.
- Cohen, L. & Manion, L. 1989. *Research methods in education*. 3<sup>rd</sup> edition. London: Routledge.
- Coleman, R. 1996. The construction of psychiatric authority. *Asylum: The Magazine for Democratic Psychiatry*. 10(1) 11–15.
- Collins, H. & Evans, R. 2002. The third wave of science studies: studies of expertise and experience. *Social Studies of Science*, 32(2): 235-96.
- Collins, R. 1990. Changing Conceptions in the Sociology of the Professions. In *The Formation of Professions: Knowledge, State and Strategy* London: Sage. Pp. 11-23.
- Coney, S. 2004. *Effective Consumer Voice and Participation for New Zealand: A Systematic Review of the Evidence*. Discussion Document. New Zealand Guidelines Group.
- Contandriopoulos, D. 2004. A sociological perspective on public participation in health care. *Social Science & Medicine*, 58(2): 321-330.

- Contandriopoulos, D., Denis, J.-L., & Langley, A. 2004. Defining the 'public' in a public health care system. *Human Relations*, 57(12):1573–1596.
- Cooper, D., Lowe, A., Puxty, A., Robson, K. & Willmott, H. 1988. *Regulating the U.K. accountancy profession: episodes in the relation between the profession and the state*. Paper presented at Economic and Social Research Council Conference on Corporation at the Policy Studies Institute, London, January, 1988.
- Cotterell, P. & Morris, C. 2012. The capacity, impact and challenge of service users' experiential knowledge. In Barnes, M. & Cotterell, P. 2012. *Critical perspectives on user involvement*. Bristol: The Policy Press, pp. 57-69.
- Cotterell, P., Harlow, G., Morris, C., Beresford, P., Hanley, B., Sargeant, A., Sitzia, J. & Staley, K. 2011. Service user involvement in cancer care: the impact on service users. *Health Expectations*, 14(2): 159-169.
- Coulter, A. 2005. What do patients and the public want from primary care? *British Medical Journal*, 331(7526): 1199-1201.
- Coupland, C. 2001. Accounting for change: A discourse analysis of graduate trainees' talk of adjustment. *Journal of Management Studies*, 38(3): 1103-1119.
- Cox, D. 1991. Health service management – a sociological view: Griffiths and the non-negotiated order of the hospital. In Gabe, J., Calnan, M. & Bury, M. (eds) *The Sociology of the Health Service*. London: Routledge. pp. 89-114.
- Crawford, M. 2001. Involving Users in the Development of Psychiatric Services – no longer an option? *Psychiatric Bulletin*. 25:84-86.
- Crawford, M. and Rutter, D. 2004. Are the views of members of mental health user groups representative of those of 'ordinary' patients? A cross-sectional survey of service users and providers. *Journal of Mental Health*, 13(6): 561–568.
- Crawford, M., Rutter, D. & Thelwall, S. 2003. *User involvement in change management: a review of the literature*. London: NHS Service Delivery and Organisation.
- Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., & Tyrer, P. 2002. Systematic review of involving patients in the planning and development of health care. *British Medical Journal*, 325(7375): 1263-1267.
- Crossley, N. 2002. Mental health, resistance and social movements: the collective confrontational dimension. *Health Education Journal*. 61(2): 138-152.
- Currie, G. & Brown, A. 2003. A narratological approach to understanding processes of organizing in a UK hospital. *Human Relations*, 56(5): 563-586.
- Currie, G., Finn, R. & Martin, G.P. 2010. Role transition and the interaction of relational and social identity: new nursing roles in the English NHS. *Organization Studies*, 31(7): 941-961.
- Currie, G., Martin, G. & Finn, R. 2009. Professional competition and modernizing the clinical workforce in the NHS: Possibilities and limits to the development of the specialist generalist in primary care. *Work, Employment and Society*, 23(2): 267-284.
- D'Sa, A., & Rigby, M. 2011. The effectiveness of the service user consultant role in specialist personality disorder services. *Mental Health Review Journal*, 16(4): 185-196.
- Daniels, M. & Johansen, E. 1985. The role of accreditation in the development of public administration as a profession: a theoretical and empirical assessment. *Public Administration Quarterly*, 8(4): 419-441.

- Davies, C. 1996. The Sociology of the Professions and the Profession of Gender. *Sociology*, 30(4): 661-678.
- Davis, J. 2000. *Identity and Social Change*. New Brunswick, NJ: Transaction Publishers.
- Daykin, N., Sanidas, M., Tritter, J., Rimmer, J., & Evans, S. 2004. Developing user involvement in a UK cancer networks: professionals' and users' perspectives. *Critical Public Health*, 14(3): 277-294.
- Della Porta, D. & Diani, M. 2006. *Social Movements: An Introduction*. 2<sup>nd</sup> edition. Oxford: Blackwell Publishing.
- Dent, M. & Whitehead, S. 2001. *Managing Professional Identities: Knowledge, Performativity and the New Professionalism*. London: Routledge.
- Denzin, N. & Lincoln, Y. 2005. Introduction The Discipline and Practice of Qualitative Research. In Denzin, N. & Lincoln, Y. (eds.) *Handbook of Qualitative Research*. 3<sup>rd</sup> edition. London: Sage.
- Denzin, N. 1989. *Interpretive Biography*. Illinois: Sage.
- Department of Health. 1991. *The Patient's Charter*. London: Department of Health.
- Department of Health. 1992. *Local voices: the views of local people in purchasing for health*. London: Department of Health.
- Department of Health. 1995. *Building Bridges: A Guide to Arrangements For Inter-agency Working for the Care and Protection of Severely Mentally Ill People*. London: Department of Health.
- Department of Health. 1999. *The National Service Framework for Mental Health. Modern Standards and Service Models*. London: Department of Health.
- Department of Health. 2000. *The NHS Plan. A Plan for Investment, a Plan for Reform*. London: Department of Health.
- Department of Health. 2001. *Involving Patients and the Public in Health Care: a discussion document*. London: Department of Health.
- Department of Health. 2003a. *Strengthening accountability: involving patients and the public: policy guidance*. London: Department of Health.
- Department of Health. 2003b. *Strengthening accountability: involving patients and the public: practice guidance*. London: Department of Health.
- Department of Health. 2004. *The NHS Improvement Plan: putting people at the heart of public services*. London: Department of Health.
- Department of Health. 2005. *Creating a Patient-led NHS. Delivering the NHS Improvement Plan*. London: Department of Health.
- Department of Health. 2007a. *House of Commons, Health Committee 2007. Patient and Public Involvement in the NHS. Third Report of Session 2006-07, Volume 1. Legislation/parliamentary/local government guidance*. London: Department of Health.
- Department of Health. 2007b. *National Stroke Strategy: practice guidance*. London: Department of Health.
- Department of Health. 2007c. *The Local Government and Public Involvement in Health Act*. London: Department of Health.
- Department of Health, 2008. *Local Authority Circular 2: Demonstrating how to deliver stroke care for adults in the community*. London: Department of Health.
- Department of Health. 2010a. *Equity and Excellence: Liberating the NHS*. London: Department of Health.

- Department of Health. 2010b. *Healthy lives, healthy people: our strategy for public health in England*. London: Department of Health.
- Department of Health. 2011. *No health without mental health: a cross-government mental health outcomes strategy for people of all ages: guidance paper*. London: Department of Health.
- Department of Health. 2012. *Liberating the NHS: No decision about me, without me*. London: Department of Health.
- Donovan, J. & Coast, J. 1996. Public participation in priority setting: commitment or illusion. In: Coast, J., Donovan, J. & Frankel, S. (eds) *Priority setting: the health care debate*. Chichester: Wiley Publishing. pp. 203–224.
- Dovi, S. 2009. In praise of exclusion. *The Journal of Politics*, 71(3): 1172–1186.
- Dryzek, J. 2001. Legitimacy and economy in deliberative democracy. *Political Theory*, 29 (5): 651-669.
- Eisenhardt, K. 1989. Building theories from case study research. *Academy of Management Review*, 14(4): 532-550.
- Eisenhardt, K. 1991. Better stories and better constructs: The case for rigor and comparative logic. *Academy of Management Review*, 8(3): 620-627.
- Eisenhardt, K. & Graebner, M. 2007. Theory building from cases: Opportunities and challenges. *Academy of Management Journal*, 50(1): 25-32.
- Elbaz, G. 1992. *The sociology of AIDS activism: The case of ACT UP/New York, 1987-1992*. Ph.D. dissertation, Department of Sociology, City University of New York.
- El Enany, N., Currie, G., & Lockett A. 2013. A Paradox in Health Care Service Development: The Professionalization of Service Users. *Social Science and Medicine*, 80: 24-30.
- Epstein, S. 1995. The construction of lay expertise: AIDS activism and the forging of credibility in the reform of clinical trials. *Science, Technology, and Human Values*, 20(4): 408-437.
- Epstein, S. 1996. *Impure Science: Aids, activism and the politics of knowledge*. University of California Press.
- Evans, L. 2008. Professionalism, professionalism and the development of education professionals. *British Journal of Educational Studies*, 56(1): 20-38.
- Eve, R., & Hodgkin, P. 1997. Professionalism and medicine. In: Broadbent, J., Dietrich, M., Roberts (eds) *The End of Professions? The Restructuring of Professional Work*. London, New York: Routledge, pp. 69-85.
- Evetts, J. 2003a. The construction of professionalism in new and existing occupational contexts: promoting and facilitating occupational change. *International Journal of Sociology and Social Policy*, 23 (4/5): 22-35.
- Evetts, J. 2003b. The sociological analysis of professionalism. Occupational Change in the Modern World. *International Sociology*, 18(2): 395-415.
- Evetts, J. 2005. The Management of Professionalism: a contemporary paradox. Paper presented to the ESRC Seminar Series, Changing Teacher Roles, Identities and Professionalism, Kings College, London.
- Evetts, J. 2006. Trust and professionalism: Challenges and occupational changes. *Current Sociology*, 54(4): 515-531.
- Evetts, J. 2011. A new professionalism? Challenges and opportunities. *Current Sociology*, 59(4): 406-422.

- Evetts, J. 2012. *Professionalism in Turbulent Times: Changes, Challenges and Opportunities*. Paper presented at the Propel International Conference, Stirling.
- Evetts, J. 2013. Professionalism: Value and ideology. *Current sociology*. Published online before print, March 12, 2013, doi:10.1177/0011392113479316.
- Exworthy, M. & Halford, S. 1999. *Professionals and the New Managerialism in the Public Sector*. Buckingham/Philadelphia: Open University Press.
- Fadden, G., Shooter, M. & Holsgrove, G. 2005. Involving carers and service users in the training of psychiatrists. *The Psychiatrist*, 29: 270-274.
- Farrell, C. & Gilbert, H. 1996. *Health care partnerships: debates and strategies for increasing patient involvement in health care and health services*. London: King's Fund Publishing.
- Fetterman, D. 1998. *Ethnography: Step by Step*. CA: Sage.
- Finn, R. 2008. The language of teamwork: Reproducing professional divisions in the operating theatre. *Human Relations*, 61(1): 103-130.
- Fitzgerald, L. & Ferlie, E. 2000. Professionals: Back to the future. *Human Relations*, 53(5): 713-739.
- Fleetwood, S. & Ackroyd, S. 2004. *Critical Realist Applications in Organization and Management Studies*, London: Routledge.
- Fletcher, G. 2003. Building sustainable partnerships in user involvement. *The Obstetrician and Gynaecologist*, 5(4): 218-20.
- Fooks, C. 2004. *Rhetoric, fallacy or dream? Examining the accountability of Canadian healthcare to citizens*. Research Report. Ottawa: Canadian Policy Research Networks.
- Forbes, T., Hallier, J. & Calder, L. 2004. Doctors as managers: investors and reluctant in a dual role. *Health Services Management Research*, 17(3):167-176.
- Foucault, M. 1980. *Power/Knowledge*. Brighton: The Harvester Press.
- Fournier, V. 1999. The Appeal to "Professionalism" as a Disciplinary Mechanism. *Social Review*, 47(2): 280-307.
- Fournier, V. 2000. Boundary work and the (un)making of the professions. In Malin, N. (Ed.), *Professionalism, Boundaries and the Workplace*, Routledge, London.
- Fournier, V. 2001. Amateurism, quackery and professional conduct: The constitution of "proper" aromatherapy practice. In Dent, M. & Whitehead, S. (eds) *Managing professional identities: knowledge, performativities and the 'new' professional*. London: Routledge, pp. 116-137.
- Fox, C. 1992. What do we mean when we say professionalism? A language usage analysis for public administration. *The American Review of Public Administration*, 22(1): 1-17.
- Fox, C. & Miller, H. 1995. *Postmodern public administration: Toward discourse*. Thousand Oaks, CA: Sage.
- Fox-Wolfgramm, S. 1997. Towards developing a methodology for doing qualitative research: The dynamic-comparative case study method. *Scandinavian Journal of Management*, 13(4): 439-455.
- Frank, A. 1990. Bringing bodies back in: a decade review. *Theory, Culture and Society*, 7(1): 131-162.
- Frankish, C.J., Kwan, B., Ratner, P.A., Wharf Higgins, J. & Larsen, C. 2002. Challenges of citizen participation in regional health authorities. *Social Science and Medicine*, 54(10): 1471-1480.

- Freidson, E. 1970. *Professional dominance: the social structure of medical care*. New York: Atherton Press.
- Freidson, E. 1982. Occupational Autonomy in Labor Market Shelters. In Steward, P. & Cantor, M. (eds) *Varieties of Work*. Beverly Hills, CA: Sage. pp. 39–54.
- Freidson E. 1986. *Professional Powers: A Study of the Professionalization of Formal Knowledge*. Chicago: University of Chicago Press.
- Freidson, E. 1988. *Profession of medicine: A study of the sociology of applied knowledge*. Chicago: University of Chicago Press.
- Freidson, E. 1994. *Professionalism Reborn: Theory, Prophecy and Policy*. Chicago: University of Chicago Press.
- Freidson, E. 2001. *Professionalism: The Third Logic*. Cambridge: Polity.
- Fotaki, M. 2011. Towards developing new partnerships in public services: Users as consumers, citizens and/or co-producers in health and social care in England and Sweden. *Public Administration*, 89(3): 933-955.
- Fudge, N., Wolfe, C. & McKeivitt, C. 2008. Assessing the promise of user involvement in health service development: ethnographic study. *British Medical Journal*, 336(7639): 313- 317.
- Fung, A., & Wright, E. 2001. Deepening democracy: innovations in empowered participatory governance. *Politics Society*, 29:5-41.
- Gastil, J., & Dillard, J. 1999. Increasing political sophistication through public deliberation. *Political Communication*, 16:3-23.
- Germov, J., 1998. Challenges to medical dominance. In Germov, J. (ed). *Second Opinion. An Introduction to Health Sociology*. Melbourne: Oxford University Press.
- Glaser, B, & Strauss, A. 1967. *The discovery of grounded theory: Strategies of qualitative research*. London: Wiedenfeld and Nicholson.
- Glaser, M. & Bryan, D. 2003. *The essential nature of the community agenda and citizen engagement: Responsiveness v. community*. Paper presented at the 64<sup>th</sup> National Conference of the American Society for Public Administration, Washington, D.C.
- Glesne, C. 1999. *Becoming Qualitative Researchers: An Introduction*. 2<sup>nd</sup> edition, New York: Longman.
- Goldthorpe, J.,1982. On the Service Class, its Formation and Future. In Giddens, A. & MacKenzie, G. (eds) *Classes and the Division of Labour: Essays in Honour of Ilya Neustadt*. Cambridge: Cambridge University Press.
- Gollust, S., Apse, K., Fuller, B., Miller, P. & Biesecker, B. 2005. Community involvement in developing policies for genetic testing: assessing the interests and experiences of individuals affected by genetic conditions. *American Journal of Public Health*, 95(1): 35-41.
- Goodman, L. 1961. Snowball sampling. *The Annals of Mathematical Statistics*, 32(1): 148-170.
- Goulding, C. 1999. *Grounded theory: some reflections on paradigm, procedures and misconceptions*. Working Paper Series, June, WP006/99, University of Wolverhampton.
- Greenhalgh, T., Humphrey, C. & Woodward, F. 2011. *User Involvement in Health Care*. Oxford: Blackwell Publishing Ltd.
- Gregory, J. 2007. *Conceptualising consumer engagement: A review of the literature*. Working Paper 1. Melbourne: Australian Institute of Health Policy Studies.

- Grunow, D. 1995. The research design in organization studies: Problems and prospects. *Organizational Science*, 6(1): 93-103.
- Guillemin, M. & Gillam, L. 2004. Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*, 10(2): 261-280.
- Gutmann, A. 2003. *Identity in Democracy*. Princeton University Press. Princeton, New Jersey.
- Gutmann, A. & Thompson, D. 2004. *Why deliberative democracy?* Princeton University Press, Woodstock.
- Gustafsson, U. & Driver, S. 2005. Parents, power and public participation: Sure Start, an experiment in New Labour governance. *Social Policy and Administration* 39(5): 528-43.
- Halford, S. and Leonard, P. 1999. Professionalism, Managerialism and the Construction of Self. In Exworthy, M. and Halford, S. (eds) *Professionals and the New Managerialism in the Public Sector*. Buckingham/Philadelphia: Open University Press. pp. 102-20.
- Halliday, T. 1987. *Beyond Monopoly: Lawyers, State Crises and Professional Empowerment*. Chicago: University of Chicago Press.
- Happell, R. & Roper, C. 2006. The myth of representation: The case for consumer leadership. *Australian e-Journal for the Advancement of Mental Health*, 5: 1446-7984.
- Harrison, S. & Ahmad, W. 2000. Medical autonomy and the UK state 1975 to 2025. *Sociology*, 34(1): 129-146.
- Harrison, S. & McDonald, R. 2008. *The Politics of Healthcare in Britain*. Sage Publications: United Kingdom.
- Harrison, S. & Mort, M. 1998. Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Social Policy and Administration*, 32(1): 60-70.
- Harrison, S. & Pollitt, C. 1994. *Controlling the Health Professionals: The Future of Work and Organisation in the NHS*. Buckingham: Open University Press.
- Haug, M. 1973. Deprofessionalization: An alternative hypothesis for the future. *Sociological Review Monographs*, 20: 195-211.
- Haug, M. 1989. A Re-examination of the Hypothesis of Physician Deprofessionalization. *The Milbank Quarterly*, 66(2): 48-56.
- Haug, M. 1975. The deprofessionalization of everyone. *Sociology focus*, 8(3):197-213.
- Hickson, D., Hinnngs, C., Lee, C, Schneck, R. and Pennings, J. 1971. A Strategic Contingencies Theory of Intra-Organizational Power. *Administrative Science Quarterly*, 16(2): 216-229.
- Hodge, S. 2005. Participation, discourse and power: a case study in service user involvement. *Critical Social Policy*, 25(2): 164-179.
- Hogg, C. & Williamson, C. 2001. Whose interests do lay people represent? Towards an understanding of the role of lay people as members of committees. *Health Expectations*, 4(1): 2-9.
- Hogg, C. 1999. *Patients, power and politics: from patients to citizens*. London: Sage.
- Hogg, C. 2007. Patient and public involvement: what next for the NHS? *Health Expectations*, 10(2): 129-138.
- Hopton, J. and Nolan, P. 2003. Involving users in mental health services. *Mental Health Practice*, 6(7): 14-18.

- Hughes, D. 1988. When nurse knows best: some aspects of nurse/doctor interaction in a casualty department. *Sociology of Health and Illness*, 10(1): 1–21.
- Irvine, R. 2002. Fabricating 'health' consumers in health care policies. In Henderson, S. & Petersen, A. (eds) *Consuming Health: the commodification of health care*. London, Routledge. pp. 31–47.
- Ives, J. Redwood, S. & Damery, S. 2012. PPI, Paradoxes and Plato: Who's sailing the ship? *Journal of Medical Ethics*. 39:181-185.
- Jamous, H. & Pelloile, B. 1970. Professions and self-perpetuating system: changes in the French university-hospital system. In Jackson, J. (ed.) *Professions and Professionalisation*. Cambridge: Cambridge University Press.
- Johnson, R. & Onwuegbuzie, A. 2004. Mixed methods research: A research paradigm whose time has come. *Educational Researcher*, 33(7): 14-26.
- Johnson, T. 1972. *Professions and power*. London: Macmillan.
- Kelly, J. 2007. Reforming public services in the UK: bringing in the third sector. *Public Administration*, 85: 1003-1022.
- Kerr, A., Cunningham-Burley, S., & Tutton, R. 2007. Shifting Subject Positions: Experts and Lay People in Public Dialogue. *Social Studies of Science*, 37(3): 385–411.
- Klein, R. 2004. The first wave of NHS foundation trusts. *British Medical Journal*, 328(7452): 1332.
- Klein, R. 2006. *The New Politics of the NHS: From Creation to Reinvention*, 5th ed. Oxford: Radcliffe Publishing.
- Kling, L., Dawes, F., & Nestor, P. 2008. Peer Specialists and Carer Consultants Working in Acute Mental Health Units: An Initial Evaluation of Consumers, Carers, and Staff Perspectives. *International Journal of Psychosocial Rehabilitation*, 12(2): 81-95.
- Knights, D. & Willmott, H. 1990. *Labour Process Theory*. London: Macmillan.
- Kolker, E. 2004. Framing as a cultural resource in health social movements: funding activism and the breast cancer movement in the US 1990- 1993. *Sociology of Health and Illness*, 26: 820-44.
- Lakeman, R., Walsh, J., & McGowan, P. 2007. Service users, authority, power and protest: A call for renewed activism. *Mental Health Practice*, 11(4): 12-16.
- Lambert, H. & Rose, H. 1996. Disembodied knowledge? Making sense of medical science. In Irwin, A. & Wynne, B. (eds) *Misunderstanding science? The public reconstruction of science and technology*. Cambridge: Cambridge University Press. pp. 65-83.
- Langley, A. 1999. Strategies for theorizing from process data. *Academy of Management Review*, 24(4): 691-710.
- Larkin, G. 1983. *Occupational Monopoly and Modern Medicine*. London: Tavistock.
- Larson M. 1990. On the matter of experts and professional, or how it is impossible to leave nothing unsaid. In *The Formation of Professions: Knowledge, State and Strategy*. London: Sage. pp. 24-36.
- Larson, M. 1977. *The Rise of Professionalism*. Berkeley, CA: University of California Press.
- Larson, M. 1979. *The rise of professionalism: A sociological analysis*. London: University of California Press.
- Lawrence, J. 2004. Mental health survivors: Your colleagues. *International Journal of Mental Health Nursing*, 13:185-190.



- Le Grand, J. 2003. *Motivation, Agency and Public Policy*. Oxford: Oxford University Press.
- Learmonth, M., Martin, G. & Warwick, P. 2009. Ordinary and effective: the catch 22 in managing the public voice in health care. *Health Expectations*, 12(1): 106-115.
- Lehoux, P., Daudelin, G., & Abelson, J. 2012a. The unbearable lightness of citizens within public deliberation processes. *Social Science & Medicine*, 74: 1843-1850.
- Lehoux, P., Daudelin, G., & Abelson, J. 2012b. A response to Martin on the role of citizens, publics and others in participatory processes. *Social Science & Medicine*, 74: 1854-1855.
- Leicht, K. & Fennell M. 2001. *Professional Work – A Sociological Approach*. Oxford: Blackwell.
- Lincoln, Y. & Guba, E. 1985. *Naturalist Enquiry* CA: Sage.
- Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J. & Morgan, K. 2002. 'The public is too subjective': public involvement at different levels of health-care decision making. *Social Science and Medicine*, 54(12): 1825-1837.
- Low J., Payne, S. & Roderick, P. 1999. The impact of stroke on informal carers: a literature review. *Social Science and Medicine*, 49(6): 711-725.
- Macdonald K. 1995. *The Sociology of the Professions* London: Sage.
- Macdonald, G. 2003. Judge or jury: involving people in decision-making. *Health Promotion International*, 13(4): 273-275.
- Macdonald, K. 1989. Building Respectability. *Sociology*, 23(1): 55-80.
- Mackay, L. 1993 *Conflicts in Care: Medicine and Nursing*, London: Chapman Hall.
- Malin, N. 2000. *Professionalism, Boundaries and the Workplace*. London: Routledge.
- Martin, G. P. 2008a. "Ordinary people only": Knowledge, representativeness, and the publics of public participation in healthcare. *Sociology of Health and Illness*, 30(1): 35-54.
- Martin, G. P. 2008b. Representativeness, legitimacy and power in public involvement in health-care management. *Social Science and Medicine*, 67(11): 1757-1765.
- Martin, G. P. 2009a. Public and user participation in public service delivery: Tensions in policy and practice. *Sociology Compass*, 3(2): 310-326.
- Martin, G. P. 2009b. Whose Health, whose care, whose say? Some comments on public involvement in new NHS commissioning arrangements. *Critical Public Health*, 19(1): 123-132.
- Martin, G. P. 2011. The third sector, user involvement and public-service reform: a case study in the co-governance of health-service provision. *Public Administration*, 89(3): 909-932.
- Martin, G. P. 2012a. Service users and the third sector: opportunities, challenges and potentials in influencing the governance of public services. In Barnes, M. and Cotterell, P. 2012. *Critical perspectives on user involvement*. Bristol: The Policy Press, pp. 47-55.
- Martin, G. P. 2012b. Citizens, publics, others and their role in participatory processes: a commentary on Lehoux et al. *Social Science & Medicine*, 74: 1851-1853.
- Martin, G. P., Currie, G., & Finn, R. 2009. Reconfiguring or reproducing intra-professional boundaries? Specialist expertise, generalist knowledge and the

- 'modernization' of the medical workforce. *Social Science and Medicine*, 68(7): 1191-1198.
- Martin, G. P. & Finn, R. 2011. Patients as team members: opportunities, challenges and paradoxes of including patients in multi-professional health-care teams. *Sociology of Health and Illness*, 33(7): 1050-1065.
- Martin, G.P., Phelps, K. & Katbamna, S. 2004. Human motivation and professional practice: of knights, knaves and social workers. *Social Policy and Administration*, 38(5): 470-487.
- Mason, J. 2002. *Qualitative Researching*. London: Sage.
- McAdam, D. & Ronelle, P. 1993. Specifying the relationship between social ties and activism. *The American Journal of Sociology*, 99(3): 640-667.
- McCann, T., Baird, J., Clark, E. & Lu, S. 2006. Beliefs about using consumer consultants in inpatient psychiatric units. *International Journal of Mental Health Nursing*, 15(4): 258-265.
- McClelland, C. 1990. Escape from freedom? Reflections on German professionalization 1870-1933. In Torstendahl, R. & Burrage, M. (eds) *The Formation of Professions: Knowledge, State and Strategy*, London: Sage. pp. 97-113.
- McIver, A. & Brocklehurst, N. 1999. Public involvement: working for better health. *Nursing Standard*, 14(1): 46-52.
- McSwite, O. 1997. Postmodernism and public administration's identity crisis. *Public Administration Review*, 57(2): 174-181.
- Middleton, P., Stanton, P. & Renouf, N. 2004. Consumer consultants in mental health services: Addressing the challenges. *Journal of Mental Health*, 13(5): 507-518.
- Miles, M. & Huberman, M. 1994. *Qualitative data analysis: An expanded sourcebook*. London: Beverley Hills.
- Milewa, T, Valentine, J. & Calnan, M. 1999. Community participation and citizenship in British health care planning: narratives of power and involvement in the changing welfare state. *Social Health Illness*, 21(4): 445-465.
- Milewa, T. 1997. User participation in service planning: a qualitative approach to gauging the impact of managerial attitudes. *Journal of Management in Medicine*, 11(4): 238-245.
- Milewa, T., Valentine, J. & Calnan, M. 1998. Managerialism and active citizenship in Britain's reformed health service: power and community in an era of decentralization. *Social Science and Medicine*, 47(4): 507-517.
- Mintzberg, H. 2004. *Managers, Not MBA's*. San Francisco, CA : Berrett Koehler.
- Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. 2011. The impact of patient and public involvement (PPI) on UK NHS healthcare: a systematic review. *International Journal for Quality in Health Care*, 24(1): 1353-4505.
- Morris, A. & Braine, N. 2001, Social movements and oppositional consciousness. In Mansbridge J. & Morris, A. (eds) *Oppositional Consciousness. The Subjective Roots of Social Protest*. Chicago: University of Chicago Press.
- Morris, J. 1998. *Encounters with strangers; feminism and disability*. London: The Women's Press.
- Mort, M., Harrison, S. & Wistow, G. 1996. The user card: picking through the organisational undergrowth in health and social care. *Contemporary Political Studies*, 2: 1133-1140.

- Mullen, P. & Spurgeon, P. 2000. *Priority Setting and the Public*. Abingdon, Oxon: Radcliff Medical Press.
- Myers F. & Macdonald C. 1996. Power to the people? Involving users and carers in needs assessment and care planning - views from the practitioner. *Health and Social Care in the Community*, 4(2): 86-95.
- Nancarrow, S. & Borthwick, A. 2005. Dynamic professional boundaries in the health care workforce. *Sociology of Health and Illness*, 27(7): 897-919.
- National Audit Office. 2005. *Reducing brain damage: faster access to better stroke care*. [www.nao.org.uk/publications/nao\_reports/05-06/0506452.pdf]
- Navarro, V. 1976. *Medicine Under Capitalism*. New York: Prodist.
- Nestor P. & Galletly C. 2008. The employment of consumers in mental health services: politically correct tokenism or genuinely useful? *Australasian Psychiatry*, 16(5): 344-347.
- Nettleton, S. & Burrows, R. 2003. E-scaped medicine? Information, reflexivity and health. *Critical Social Policy*, 23(2): 165-185.
- Newman, J. 2001. *Modernising governance: New Labour, policy and society*. Sage, London.
- Newman, J., Barnes, M., Sullivan, H. & Knops, A. 2004. Public participation and collaborative governance. *Journal of Social Policy*, 33(2): 203-223.
- Nightingale, D. & Cromby, J. 1999. *Social Constructionist Psychology*. Buckingham: Open University Press.
- Noordegraaf, M. & Van Der Meulen, M. 2008. Professional power play: organizing management in health care. *Public Administration*, 86(4): 1055-1069.
- Noordegraaf, M. 2007. From pure to hybrid professionalism: present-day professionalism in ambiguous public domains. *Administration & Society*, 39(6): 761-785.
- Norman, J. 2010. *The Big Society*. Buckingham: Buckingham University Press.
- Oliver, S., Clarke-Jones, L., Rees, R., Milne, R., Buchanan, P., Gabbay, J., Gyte, G., Oakley, A. & Stein, K. 2004. Involving consumers in research and development agenda setting for the NHS: Developing an evidence-based approach. *Health Technology Assessment*, 8(15): 1-148.
- Parkin, F. 1971. *Class inequality and political order*. London: Macgibbon and Kee.
- Parkin, F. 1979. *Marxism and class theory: A bourgeois critique* London: Tavistock.
- Parkinson, J. 2003. Legitimacy problems in deliberative democracy. *Political Studies*, 51(1): 180-196.
- Parsons, T. 1951. *The social system*. New York: Free Press.
- Parsons, T. 1954. *Essays in sociological theory*. New York: Free Press.
- Patton, M. 2002. *Qualitative Research and Evaluation Methods*. 3<sup>rd</sup> edition. CA: Sage Publications.
- Pettigrew, A. 1985. *The Awakening Giant: Continuity and Change in Imperial Chemical Industries*. Oxford: Blackwell.
- Pettigrew, A. 1992. The character and significance of strategy process research. *Strategic Management Journal*, 13(Special Issue): 5-16.
- Pettigrew, A., Ferlie, E. & Mckee, L. 1992. *Shaping Strategic Change. Making Change in Large Organizations: The Case of the National Health Service*. London: Sage.
- Pfeffer, J. 1982. *Organizations and organization theory*. Marshfield, MA: Pitman.

- Pickard, S. & Smith, K. 2001. A 'Third Way' for lay involvement: what evidence so far? *Health Expectations*, 4(3): 170-179.
- Pilgrim, D. & Rogers, A. 1999. *A sociology of mental health and illness*, Buckingham: Open University Press.
- Pope C., Ziebland, S., & Mays N. 2000. Qualitative research in health care: Analysing qualitative data. *British Medical Journal*, 320(7227): 114-116.
- Porter, S. 1991. A participant observation study of power relations between doctors and nurses in a general hospital. *Journal of Advanced Nursing*, 16(6): 728-735.
- Potter, D. 2010. Wrong parents' and 'right parents': Shared perspectives about citizen participation in policy implementation. *Social Science and Medicine*, 70(11): 1705-1713.
- Prior, D., Stewart, J. & Walsh, K. 1995. *Citizenship: rights, community and participation*. Pitman Publishing, London
- Prior, L. 2003. Belief, knowledge and expertise: the emergence of the lay expert in medical sociology. *Sociology of Health and Illness*, 25(Silver Anniversary Issue): 41-57.
- Pyke, J., Samuelson, G., Shepherd, M. & Brown, N. 1991. Shaping mental health services. *Canadian Nurse*, 87(5): 17-19.
- Ragin, C. 1997. Turning the tables: How case-oriented research challenges variable-oriented research. *Comparative Social Research*, 16:27-42.
- Reed, M. 1996. Expert power and control in late modernity: an empirical review and theoretical synthesis, *Organization Studies*, 17(4): 573-597.
- Reed, M. 2005. Reflections on the realist turn in organization and management studies. *British Journal of Management Studies*, 42(8): 1621-1644.
- Rhodes, P., Nocon, A., Booth, M., Chowdrey, M.Y., Fabian, A., Lambert, N., Mohammed, F. and Walgrove, T. 2002. A service users' research advisory group from the perspectives of both users and researchers. *Health and Social Care in the Community*, 10(5): 402-409.
- Richards, T. & Richards, L. 1994. Using computers in qualitative research, In Denzin, N. and Lincoln, Y. (eds) *Handbook of qualitative research*. Thousand Oaks: Sage.
- Ridley, J. & Jones, L. 2001. *User and Public Involvement in Health Services: A Literature Review, Partners in Change*. NHS Health Scotland and Scottish Executive.
- Robson, C. 1993. *Real world research: A resource for social scientists and practitioner-researchers*. Oxford: Blackwell.
- Rogers, A., Pilgrim, D. & Lacey, R. 1993. *Experiencing Psychiatry: Users' Views of Services*. London: Macmillan/MIND.
- Rose, D., Fleischmann, P. & Schofield, P. 2010. Perceptions of User Involvement: A User-Led Study. *International Journal of Social Psychiatry*, 56(4): 389-401.
- Rowe, R. & Shepherd, M. 2002. Public participation in the new NHS: no closer to citizen control? *Social Policy and Administration*, 36(3): 275-290.
- Roy, C. & Cain, R. 2001. The involvement of people living with HIV/AIDS in community-based organizations: contributions and constraints. *AIDS Care*, 13(4): 421-432.
- Rush, B. 2004. Mental health service user involvement in England: lessons from history. *Journal of Psychiatric and Mental Health Nursing*, 11(3): 313-318.

- Rutter, D., Manley, C., Weaver, T., Crawford, M., Fulop, N. 2004. Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 58(10): 1973-1984.
- Ryfe, D. 2002. The practice of deliberative democracy: a study of 16 deliberative organizations. *Political Communication*, 19(3): 359-377.
- Ryfe, D. 2005. Does deliberative democracy work? *Annual Review of Political Science*, 8:49-71.
- Sanders, T. & Harrison, S. 2008. Professional legitimacy claims in the multidisciplinary workplace: The case of heart failure care. *Sociology of Health and Illness*, 30(2): 289-308.
- Saunders, M., Lewis, P. & Thornhill, A. 2003. Deciding on the research approach and choosing a research strategy. In Saunders, M., Thornhill, A. & Lewis, P. (eds), *Research methods for business students*. 3<sup>rd</sup> edition. London: Prentice Hall Financial.
- Saward, M. 2000. Less Than Meets the Eye: Democratic Legitimacy and Deliberative Theory, in M. Saward (ed.), *Democratic Innovation: Deliberation, Representation and Association*. pp. 66-77. London: Routledge.
- Saward, M. 2006. The Representative Claim. *Contemporary Political Theory*, 5: 297-318.
- Scheff, T. 1966. *Being mentally ill: A sociology theory*. Chicago: Aldine.
- Schein, E. 1996. Culture: The missing concept in organization studies. *Administrative Science Quarterly*, 41(2): 229-240.
- Scott, R. 2008. Lords of the dance: Professionals as institutional agents. *Organization Studies*, 29(2): 219-223.
- Silverman, D. 1985. *Qualitative methodology and sociology*. Aldershot: Gower.
- Silverman, D. 1997. *Qualitative research: Theory, method and practice*. London: Sage Publishing.
- Silverman, D. 2000. *Doing qualitative research: A practical handbook*. London: Sage Publishing.
- Silverman, D. 2001. *Interpreting qualitative data: Methods for analysing talk, text and interaction*. London: Sage Publishing.
- Silverman, D. 2006. *Interpreting qualitative data: Methods for analyzing talk, text and interaction*. 3<sup>rd</sup> edition. London: Sage Publishing.
- Silverman, D. 2009. *Doing qualitative research*. London: Sage Publishing.
- Simpson, E. & House, A. 2002. Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*, 325(7375): 1265-1268.
- Spiggle, S. 1994. Analysis and interpretation of qualitative data in consumer research. *Journal of Consumer Research*, 21(3): 491-503.
- Spivak, G. 1988. Can the Subaltern Speak? In Nelson, C. & Grossberg, L. (eds.). *Marxism and the Interpretation of Culture*. Urbana, Chicago: University of Illinois Press.
- Stake, R. 2005. Qualitative case studies. In Denzin, N. & Lincoln, Y. (eds) *The Sage handbook of qualitative research design*. CA: Sage.
- Staley, K. 2013. There is no paradox with PPI in research. *Journal of Medical Ethics*. 39(3): 186-187.

- Starr, P. 1982. *The Social Transformation of American Medicine*. New York: Basic Books.
- Stern, D. 2006. *Measuring Medical Professionalism*. New York: Oxford University Press.
- Stickley, T. 2006. Should service user involvement be consigned to history? A critical realist perspective. *Journal of Psychiatric and Mental Health Nursing*, 13(5): 570-577.
- Strasser, S. & Davis, R. 1991. *Measuring Patient Satisfaction for Improved Patient Services*. Michigan: American College of Healthcare Executives.
- Strauss, A. 1991. *Qualitative Analysis for Social Scientists* New York: Cambridge University Press.
- Strauss, A. & Corbin, J. 1990. *Basics of Qualitative Research: grounded theory procedures and techniques*. London: Sage.
- Stryker, S. 2000. Identity competition: Key to differential social movement involvement. In Stryker, S., Owens, T. & White, R. (eds) *Identity, self, and social movements* Minneapolis: University of Minnesota Press. pp. 21-40.
- Suddaby, R. 2006. What grounded theory is not. *Academy of Management Journal*, 49(4): 633-642.
- Swick, H. 2000. Toward a Normative Definition of Medical Professionalism. *Academic Medicine*, 75(6): 612-616.
- Svensson, R. 1996. The interplay between doctors and nurses: a negotiated order perspective, *Sociology of Health and Illness*, 18(3): 379-398.
- Taylor, B. 1995. Amateurs, Professionals and the Knowledge of Archaeology. *The British Journal of Sociology*, 46(3): 499-508.
- Teske, N. 1997. *Political activists in America. The identity construction model of political participation*. Cambridge, UK: Cambridge University Press.
- Thompson, J., Bissell, P., Cooper, C., Armitage, C. & Barber, R. 2012. Credibility and the 'professionalized' lay expert: Reflections on the dilemmas and opportunities of public involvement in health research. *Health*, 16(6): 602-618.
- Thorne, M. 2002. Colonizing the new world of NHS management: the shifting power of professionals. *Health Services Management*, 15(1): 14-26.
- Thornicroft, G. 2000. National Service Framework for Mental Health. *Psychiatric Bulletin*, 24(6): 203-206.
- Timmons, S. & East, L. 2011. Uniforms, status and professional boundaries in hospital. *Sociology of Health and Illness*, 33(7): 1035-1049.
- Tritter, J. & Koivusalo, M. 2013. Undermining patient and public engagement and limiting its impact: The consequences of the Health and Social Care Act 2012 on collective patient and public involvement. *Health Expectations*, 16:115-118.
- Tritter, J. & McCallum, A. 2006. The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2): 156-168.
- Tritter, J., Daykin, N., Evans, S. & Sanidas, M. 2003. *Improving cancer services through patient involvement*. Oxford: Radcliffe Medical Press.
- Turner, B. 1988. *Status* Milton Keynes: Open University Press.
- Turner, B. 1995. *Medical Power and Social Knowledge*. 2<sup>nd</sup> edition. London: Sage.
- Thwistlethwaite, J & Spencer, J. 2008. *Professionalism in medicine*. United Kingdom: Radcliffe Publishing Ltd.
- Van de Ven, A. & Huber, G. 1990. Longitudinal field research methods for studying processes of organizational change. *Organization Science*, 1(3): 213-129.

- Vigoda, E. 2002. From responsiveness to collaboration: governance, citizens, and the next generation of public administration. *Public Administration Review* 62(5): 527-540.
- Waitzkin, H. 1989. A critical theory of medical discourse: Ideology, social control, and the processing of social context in medical encounters. *Journal of Health and Social Behavior*, 30(2): 220-239.
- Wallcraft, J., Read, J. & Sweeney, A. 2003. *On our own terms*. London: Sainsbury Centre for Mental Health.
- Waring, J., & Currie, G. 2009. Managing Expert Knowledge: Organizational Challenges and Managerial Futures for the UK Medical Profession. *Organization Studies*, 30(7): 755-778.
- Watson, T. 1977. *The Personnel Managers: A Study in the Sociology of Work and Industry*. London: Routledge.
- Weber, M. 1978. *Economy and Society*. London: University of California Press.
- Weinstein, J. 2010. *Mental Health, Service User Involvement and Recovery*. London: Jessica Kingsley Publishers.
- Wellard, S., Lillibridge, J., Beanland, C. & Lewis, M. 2003. Consumer participation in acute care settings: an Australian experience. *International Journal of Nursing Practice*, 9(4): 255-260.
- Whelan, E. 2007. 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community. *Sociology of Health and Illness*, 29(7): 957-982.
- White, D. 2000. Consumer and community participation: a reassessment of process, impact and value. In: Albrecht, G., Fitzpatrick, R., Scrimshaw, S. (eds) *Handbook of social studies in health and medicine*. London: Sage Publishing. pp. 465-480.
- White, R. & Fraser, M. 2000. Identity competition: Key to differential social movement involvement. In Stryker, S., Owens, T. & White, R. (eds) *Identity, self, and social movements*. Minneapolis: University of Minnesota Press. pp. 324-344.
- Wicks, D. 1998. *Nurses and Doctors at Work: Rethinking Professional Boundaries*. Milton Keynes: Open University Press.
- Wilensky, H. 1974. The Professionalization of Everyone? *The American Journal of Sociology*, 70(2): 137-158.
- Williams, M. 2004. Discursive democracy and New Labour: five ways in which decision-makers manage citizen agendas in public participation initiatives. *Sociological Research Online*, 9(3) [<http://www.socresonline.org.uk/9/3/williams.html>]
- Williamson, T. 2004. User involvement - a contemporary overview. *Mental Health Review*, 9(1): 6-12.
- Willmott, H. 2005. Theorizing Contemporary Control: Some Post-Structuralist Responses to Some Critical Realist Questions, *Organization*, 2(5): 747-780.
- Witz, A. 1992. *Professions and Patriarchy*. London: Routledge.
- Wright, B. 2013. Do patients have a voice? The social stratification of health center governing boards. *Health Expectations*. Published online before print, 25 February 2013, doi: 10.1111/hex.12059.
- Wolfe, C. 2000. The impact of stroke. *British Medical Bulletin*. 56(2): 275-286.
- Yin, R. 1984. *Case study research: Design and methods*. Newbury Park, CA: Sage.
- Yin, R. 1994. *Case study research; design and methods*. London, Sage.

- Yin, R. 2003. *Case study research, design and methods*. 3<sup>rd</sup> edition. Newbury Park: Sage Publications.
- Young, I. 2000. *Inclusion and Democracy*. Oxford, UK: Oxford University Press.
- Young, R., Leese, B. & Sibbald, B. 2001. Imbalances in the GP labour market in the UK: evidence from a postal survey and interviews with GP leavers. *Work, Employment and Society*, 15(4): 699-729.
- Zartman, W. 2005. Comparative Case Studies. *International Negotiation*, 10(1): 3-16.
- Ziebland, S. 2004. The importance of being expert: the quest for cancer information on the Internet. *Social Science and Medicine*, 59(9): 1783-1793.
- Zola, I. 1972. Medicine as an institution of social control: The medicalizing of society. *Sociological Review*, 20(4): 487-504.