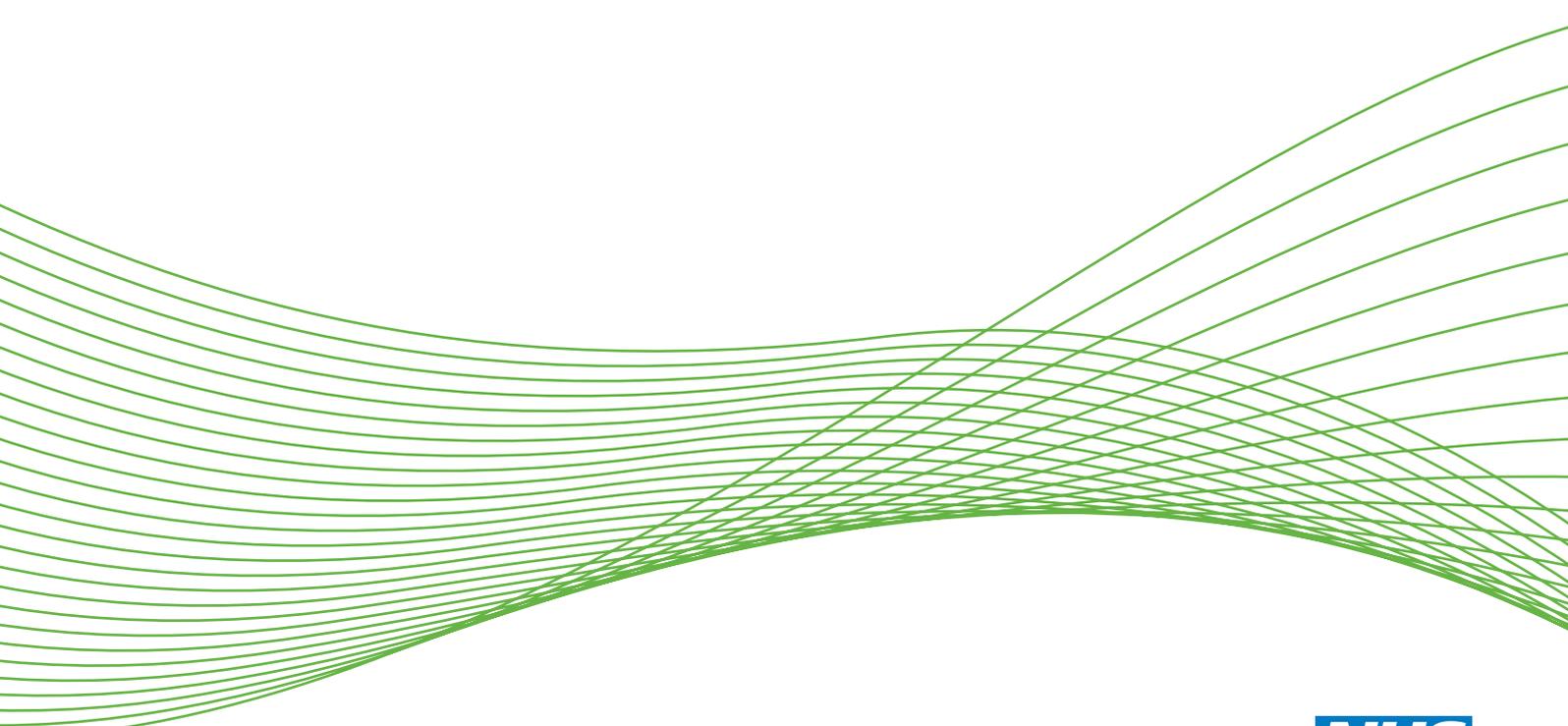


How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study

Diana Rose, Marian Barnes, Mike Crawford, Edward Omeni, Dee MacDonald and Aaron Wilson



***National Institute for
Health Research***

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Disclaimer: This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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Abstract

How do managers and leaders in the National Health Service and social care respond to service user involvement in mental health services in both its traditional and emergent forms? The ENSUE study

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Background: This study set out to measure the extent and perceived impact of service user involvement (SUI) in mental health services and to explore different forms of SUI, both collective and individual. The focus was on service users' (SUs') interactions with managers and other key decision-makers in the UK NHS and social care. The theoretical frameworks used were organisational theory and new social movement theory.

Objectives: To explore the impact of service user involvement in mental health on shaping policy agendas and delivery specifically in terms of their impact on key decision-makers.

Design: A mixed-methods design was used.

Setting: The study took place in three NHS foundation trusts (FTs): two metropolitan and one rural.

Methods: The methods included surveys, interviews, ethnographies, case studies and focus groups.

Results: In the first phase of the study, which took the form of surveys, it was found that 'ordinary' SUs had a relatively high level of involvement in at least one service domain and that where they were involved they believed this had produced a positive impact on service development and delivery. Likewise a majority of front-line staff encouraged SUI and thought this had a positive impact although social workers were more likely to have directly participated in SUI initiatives than nurses. In the second phase of the study, which used qualitative methods, an ethnography of user-led organisations (ULO) was conducted, which showed that ULOs were being forced to adapt in an organisational climate of change and complexity, and that decision-makers no longer claimed the high moral ground for working with ULOs, but expected them to work within a system of institutional behavioural norms. This posed many challenges for the ULOs. In phase 2 of the research we also examined the role of SU governors in NHS FTs. We posed the question of whether or not SU governors represented a shift away from more collective forms of organisation to a more individual form. It was found that SU governors, too, had to work within a system of norms deriving from the organisational structure and culture of the NHS, and this impacted on how far they were able to exercise influence. There was also evidence that user governors were beginning to organise collectively. In respect of individual forms of involvement we also attempted to run focus groups of people in receipt of personal budgets but concluded that, as yet, they are not embedded in mental health services.

Conclusions: It was concluded that SUs and managers are working in a climate of dynamic and complex organisational change, of which user involvement is an integral part, and that this has impacted on the nature of SUI as a new social movement. Managers need to attend to this in their interactions with SUs and their organisations.

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List of abbreviations

BME	black and minority ethnic	MHRN	Mental Health Research Network
CCG	Clinical Commissioning Group	NGO	non-governmental organisation
CEO	chief executive officer	NSUN	National User and Survivor Network
CHC	community health council	PALS	Patient Advice and Liaison Service
CofG	Council of Governors	PCT	primary care trust
CMHT	Community Mental Health Team	PPI	patient and public involvement
CPN	community psychiatric nurse	SDS	self-directed support
CTO	Community Treatment Order	SU	service user
FACS	Fair Access to Care Services	SUI	service user involvement
FT	foundation trust	ULO	user-led organisation
IRG	Internal Reference Group		
LINKS	local involvement networks		

Plain English summary

User involvement in mental health services was established before involvement in most other medical specialties and could be said to have taken the form of a 'new social movement'. Early literature suggested that, when it came to involvement in the UK NHS and social care, service users (SUs) and their organisations struggled to have a real impact on decision-making at either individual or strategic levels. The aim of the present study was to find out how user involvement is faring currently. We discovered that 'ordinary' SUs do have some involvement in service planning and delivery; they regard this as having a positive impact; and they are supported by both front-line and senior staff. In studying user-led organisations, we found that they are working in a climate of organisational change and complexity that has forced them to adapt and change, such that 'traditional' styles of confrontation and campaigning have given way to the adoption of more corporate and professional modes. However, this posed many challenges for the organisations we studied. In addition, new opportunities and forums have opened up for user involvement, including the possibilities of becoming members and governors of NHS foundation trusts. When we looked at these, similar issues of appropriate styles of behaviour and negotiation arose. Personalisation is another way in which SUs may control their own care, but we found little evidence that this is happening. We therefore recommend that more research be carried out on the applicability of personalisation to the field of mental health.

Scientific summary

Background

The background to this report is the increasing policy emphasis on user involvement in health service planning and delivery, specifically in mental health, and theoretical frameworks concerned with organisational change and new social movements. The study comprises primary research following on from literature reviews conducted by two members of the research team. It has strong patient and public involvement.

Objectives

The following research questions were asked:

1. What have been the impacts of user involvement in mental health in terms of service development, delivery, commissioning and personal benefit to users? We have the same research question for front-line staff.
2. How do managers and other key decision-makers respond when user-led organisations (ULO) approach them, seeking change?
3. Moving to a more individual level of user involvement, what is the role played by user governors on trust boards and how do key decision-makers on the boards respond to them?
4. What are the implications of the move to 'personalisation' in both health and social care, specifically in terms of the role of ULOs in brokerage and care planning?
5. What are the underlying assumptions, beliefs and values held by senior managers about the benefits and drawbacks of user involvement in mental health, and how do they individually and collectively respond to, facilitate or impede this?

Methods

The study took place in three UK NHS foundation trusts, two metropolitan and one rural. Quantitative methods, in the form of surveys of service users (SUs) and front-line staff, were used to answer research question 1. Service users were recruited from outpatient clinics and day centres, and front-line staff were sent an electronic survey via their human resources department. As part of this study of impact, semistructured interviews were also conducted with 24 senior members of staff. Research question 2 was approached using ethnographic and case study methods. We worked with six ULOs. They were asked to identify a goal that would involve them in interactions with managers and these interactions were observed, as were the meetings of the organisations themselves. Two members of each ULO kept reflective diaries. The ethnography lasted, on average, for 1 year. For research question 3, Council of Governor meetings were observed and, in one case, subcommittees of the Council were also observed. Focus groups were conducted with user governors and the chairperson of the Council of Governors (CofG) was interviewed. The aim was to find out how much influence the user governors had and whether or not this development represents a shift from more collective to more individual forms of involvement. For research question 4, we held focus groups with SUs who were in receipt of personal budgets, with the aim of finding out about their experience of the assessment process, how they spent money allocated and whether they did this at a collective ('pooled') or individual level. For research question 5, we convened a deliberative workshop of the senior staff interviewed in phase 1 and presented our main findings to them. The aim of the workshop was for them to help us interpret our findings from the perspective of key decision-makers.

Results

The survey of SUs showed that 'ordinary' users of mental health services did have some involvement in service planning and delivery. This marks a change from 20 years ago. Where SUs were involved, they overwhelmingly thought that this had a positive impact. Staff were also found to encourage service user involvement (SUI) in the planning and delivery of care. Younger staff, and those with a social work background, as opposed to a nursing professional background, were more likely to believe that involvement is having a positive impact. In free-text responses, both SUs and staff mentioned having a voice and shaping services, as well as empowerment, as positive benefits of user involvement. Disadvantages included tokenism and stress for both groups.

For all the qualitative work, which delved more deeply into user involvement activities, a major finding was the scale of change and complexity in organisations in which SUs and their organisations were trying to effect change. This impacted on staff, both front-line and senior, as well. The ULOs had to adapt to the changing and dynamic organisational context and this posed many challenges. One of the groups, which prized its autonomy and its campaigning stance, actually failed during the time of the ethnography and this seemed to be because it could neither comply with the behavioural norms of the current negotiating context nor ally itself with other user-focused organisations in a way that both commissioners and providers expected. Other ULOs adopted the strategy of both specialising – for example concentrating on one group of mental health SUs, focusing on creative activities or on evaluation and research – and complying much more with the corporate demands of behaviour, professionalism and language of key decision-makers and the mental health system. However, such success as they achieved was often partial or bought at a price. Thus, a research group had to function in the context of other stakeholders who valued grant income and publications over user involvement in their research, and the group representing an underserved population had to relinquish some control to a much larger voluntary organisation. A group that did try to intervene on a county-wide basis in the rural trust found itself struggling for representation in a provider forum as well as in conflict with the local Patient Advice and Liaison Service. This was not an isolated case. The group also experienced a considerable stretching of its resources.

The observations of, and focus groups with, user governors also showed the impact of organisational complexity and the demands of operating within the contemporary NHS. User governors had to adopt the language and behaviour of formal meetings otherwise they were deemed 'inappropriate'. There were variations between the trusts. One metropolitan trust had set up a complex series of subcommittees, one of which was chaired by a user governor, and here the institutional rules and norms were more relaxed. The participants in the focus group for this trust were positive about the influence they were able to exert. In the other metropolitan trust the participants were negative to the point of being angry and said that they were unclear about their roles and responsibilities. The research team had great difficulty gaining access to this CofG and to the user governors themselves, and it seemed that the trust had some distance to travel before user governors could become a real and effective part of the landscape. In the rural trust there was also some disquiet but also, towards the end of the observation period, some evidence that the user governors wanted to meet together and exert some collective influence. A further issue was that of representation, something that has beset SUI in mental health service planning and delivery since the outset and appears here in a new guise as a 'democratic' concept of representation rather than one based on typicality. Finally, we found that informal networking opportunities were just as important as formal meetings with respect to SU governors having an impact.

Personalisation and individual commissioning are government policy. Our intention had been to run two focus groups with people in receipt of personal budgets in each trust. This proved impossible. Recruitment was very difficult because it was hard to find anyone who was indeed in receipt of a personal budget. Those who came forward often were receiving other welfare benefits or even wanted to attend the focus group as a route to getting a personal budget. We were able to run only one focus group per trust and the discussions centred on the assessment process, how complex it is, and how the Fair Access to Care assessment is inappropriate to those with mental health needs. We held one group in an arts venue,

where individuals were pooling their budgets to 'buy' an arts class. Our research question included the place of ULOs as brokers for personal budgets, in place when we wrote our protocol, but these were not in evidence.

The deliberative workshop for senior staff generated three main issues. One was to do with the reconfiguration of mental health trusts, the provision of services outside the geographical area and the consequent rupture between service provision and locality-based user involvement activities. Second, it was noted that our focus on normative language was perhaps misplaced because 'management speak' is empty. At least, this has to be refined as there are contexts in which the voices of experience, or SUs' stories, are valued. Staff training is a case in point where it is helpful to hear about living with a mental health condition and the experience of receiving treatments and services. Finally, some senior staff were of the view that how user involvement is conducted should be left to SUs themselves and their organisations. It was pointed out that our findings concerning institutional rules and norms and organisational complexity mean that there is a context that defines what can and cannot be done, which is not in the control of either SUs or staff.

Conclusions

We conclude that the organisational change and complexity that has characterised the NHS and social care in recent decades, and which was heightened at the time of our research, has shifted what mental health SUs and their organisations are able to achieve. At the same time, SUI has become an integral part of the system. Old-style ULOs find it difficult to survive in this climate and, so, groups have adapted and mental health SUs have taken up new roles, for example as user governors. Our hypothesis that we are witnessing a shift from more collective to more individual forms of involvement needs to be refined, and is rendered more complex owing to evidence that mental health SUs are unwilling to give up a collective voice. However, this new social movement has certainly changed in the last 30 years. It has become an established part of the landscape but in the process has had to adapt. Managers and decision-makers need to attend to this new configuration in their interactions with SUs and their organisations.

Our main implication for health-care concerns personalisation and individual commissioning. This is hailed as a major transfer of power from state to citizen. However, what we found was confusion, bewilderment and fear that welfare benefits would be lost at the same time as valued services such as day centres were cut. We did, of course, look only at mental health SUs, and personalisation has been drawn in the image of support for people with physical and sensory impairments. More research in this area is urgently required.

Funding

Funding for this study was provided by the Health Services and Delivery Research programme.

Chapter 1 Introduction

Policy

It is nearly 25 years since the Griffiths Report of 1989 ushered in the *National Health Service and Community Care Act 1990*,¹ which first enjoined local authorities to consult with their local publics on their community care plans. At that point, not all long-stay institutions for those with mental health conditions had been closed and for that population community care was in its infancy. At the same time the previous decade had seen a burgeoning of local and national organisations of mental health service users (SUs), arguably made possible by the closing of the long-stay institutions which left ex-residents free to organise. These organisations were often vocal and sometimes angry. We will revisit them later in this report.

The 1990 Act also introduced the purchaser/provider split so positioning the public as 'consumers' in a market. In effect, this was a quasi-market, as providers had a monopoly and there was little freedom to choose. This was particularly the case for some mental health SUs who receive services under compulsion and, therefore, cannot walk away from services or turn to an alternative provider. Unlike the situation in a full or even a quasi-market, they have no right of 'exit' and, so, the expression of their needs and wishes must rely on 'voice'. In the chapter concerning user-led organisations (ULOs) we will consider what this means in organisational terms. It can also be noted here that very recent legislative change, in the form of the *Health and Social Care Act 2012*, increases the market in health care, but it remains unclear what this will entail for users of mental health services, particularly those regarded as in need of high-intensity care.

In terms of user involvement, the 1990 Act proved a watershed, as successive administrations incrementally put an emphasis on user and carer involvement in health service design and delivery, including in mental health. In 1995, the Health and Social Care Advisory Service (HASCAS) evaluated the National Institute for Mental Health in England (NIMHE) and recommended strengthening its user involvement strategies. The conservative administration of the late 1980s and 1990s convened a Mental Health Task Force, and included a SU group that wrote its own 'Charter of Demands'. The New Labour government appeared to continue these developments with the 1999 National Service Framework for Mental Health,² declaring user involvement as one of its core principles, and including SUs on the Internal Reference Group that compiled the document. However, the momentum was not without its critics. In July 1998, the then-Secretary of State for Health, Frank Dobson, declared that 'community care has failed', leaving vulnerable patients at risk of harm to themselves and others. This presaged a continuing ambivalence around those with a mental health condition – the imperative of choice faced with a concern about risk – that permeated its 1999 policy document *Modernising Mental Health Services: Safe, Sound and Supportive*.³

Further, the Mental Health Task Force was abolished by New Labour and, with it, the national user group. The NHS Plan⁴ promised 'patient-centred care' across the whole NHS and this, perhaps, was the seedbed for something more individual to replace collective involvement, something we shall consider presently. Equally, the move to foundation trusts (FTs), with member and governor status open to constituencies, which included patients/SUs, enabled individuals to hold power without representing specific ULOs, although they were not prevented from making the link if they so wished. Finally, on this note, a further policy change likely to impact on user involvement is 'personalisation', first mooted by the government in 2007⁵ and then firmed up by proposals for transferring finances from service providers to SUs.⁶ Personalisation emphasises *individual* choice and commissioning, whereas previous initiatives have sought to enable mental health SUs to impact on commissioning and service delivery collectively. The focus on individual commissioning is despite the fact that the Department of Health stipulated that local authorities should have a ULO working with them to implement the policy. In the evaluation of the first pilot sites,⁷ this did not always work well and now it seems to have been quietly put aside.

As a result of national policy change, the 1990s and early 2000s saw community health councils abolished at a local level and replaced, first with patient and public involvement (PPI) fora and then by local involvement networks (LINKS), the role of which was to advise commissioners on local health needs and also have powers to make visits to local health providers. LINKS themselves are due to give way to Healthwatch organisations. The rapid turnover for mechanisms of involvement at a local level indicates some problems. However, traditionally, the mental health voice has been strong in the local involvement arena and it is perhaps here that collective involvement has been most successful.

The last policy document on mental health issued by the last Labour administration was entitled 'New Horizons'.⁸ An innovation that was to be picked up by the new coalition government was an emphasis on the well-being of the whole population and not just better services for those with poor mental health, although these were promised too. There was also a move to the language of responsibility for one's own well-being, as well as choice (despite the fact that mental health SUs were the one group denied choice of providers). The other important document produced by the last Labour administration was Lord Darzi's *High Quality Care for All*,⁹ which continued the modernisation agenda but with a very strong emphasis on quality and patient choice. Including the first NHS constitution, the report also for the first time put the spotlight on the patient experience. This focus on the patient experience represents a subtle shift from service user involvement (SUI) as traditionally understood, as we shall see later. There was also no attempt by Lord Darzi to extend NHS Choices to those receiving mental health services.

Most of the changes wrought by the current administration do not need to be rehearsed here.¹⁰ Suffice to say that any user involvement in commissioning must now look quite different to when primary care trusts (PCTs) were the key commissioning bodies. There is promised patient and public involvement in Clinical Commissioning Groups (CCGs), although how 'involvement' is to be defined and practised rests with local decision-makers as befits the new 'localism' of current policy. MIND has counselled a 'coproduction' model. At the same time, a report from the NHS Futures Forum,¹¹ which commented on the document *Equity and Excellence: Liberating the NHS*,¹² counselled both shared decision-making in clinical care and public accountability through patient and public involvement in governance. The report also called for a better definition of patient involvement, indicating that this is a perennial problem. The extent to which the *Health and Social Care Act 2012*¹⁰ incorporated these recommendations is unclear but would seem to focus on the former rather than the latter. In this context, it is interesting that Perestelo-Perez *et al.*¹³ argue that mental health is a particularly challenging area for shared decision-making.

Healthwatch, both locally and nationally, would seem to be the most appropriate body for ensuring patient and public involvement at the levels of governance and accountability, but we must await their proper formation as these bodies are being set up as we prepare this report. The National User and Survivor Network (NSUN) is making strenuous efforts to include a mental health SU voice on Healthwatch. The emphasis on the patient experience as opposed to more collective involvement is one option in the new configuration of the NHS and we will take this up further in later chapters. However, the coalition has produced a white paper specifically on mental health and this warrants comment.

*No Health Without Mental Health*¹⁴ and its Implementation Framework¹⁵ seek parity between physical and mental health, true choice of provider for those with a mental health problem and an end to discrimination on mental health grounds. There is an emphasis on recovery and the coalition has continued with the policy of personalisation. It first promised that personalisation would be rolled out to all in receipt of social care soon after it was elected, but had to revise this to 70% in light of practical difficulties. Personalisation of health budgets is being trialled and there is also a promise that these will eventually be universal. However, there is now no mention of a role for ULOs. We shall see in this report that, although personalisation is a key policy for the current government, it is difficult still to identify people who are in receipt of personal or individual budgets in the mental health domain.

Patient and public involvement in mental health services has a long history, as we have seen. We have briefly traced how it has been developed and reconfigured in the last decades. Our report spans the

first 2 years of the current coalition government and in it we take an in-depth look at how user involvement in mental health is faring, from the perspective of both SUs and managers/providers, in the dynamic and changing climate in which we find ourselves now.

Theoretical frameworks

A new social movement?

It has been argued that the emergence of mental health activist groups, at both national and local levels, constitutes a new social movement in the image of black and women's movements. Although patients from other medical specialties may have organised for improvements in their care and for mutual support,¹⁶ mental health SU organisations sought wholesale change in services and in their conditions of living. Crossley¹⁷ traces this back to the beginnings of charitable organisations for the mentally ill between the World Wars and uses social network theory to map the various configurations of the movement as it developed. He gives a pivotal role to the antipsychiatry movement in England, with iconic figures such as Ronald Laing and David Cooper seen as key. It is argued that mental health SUs represent a group ready to form a new social movement because the practices of psychiatry (diagnostic and therapeutic), as well as its coercive possibilities, mark its users off from other medical patients as disempowered or even oppressed. Other health groups have, of course, organised in the past but usually about a cure for their condition rather than their overall situation. An example is the struggle between young men infected with human immunodeficiency virus (HIV) or with acquired immunodeficiency syndrome (AIDS) and pharmaceutical companies and regulatory authorities.¹⁸ Nevertheless, this was situated in a gay and lesbian discourse and so could also be seen as embedded in a new social movement.

As far as mental health SUs are concerned, it is also notable that they have organised outside and before 'official' involvement initiatives, with user groups emerging in the 1970s and a burgeoning of activity in the 1980s at national level, well before legislation in support of user involvement was first enacted. Lindow¹⁹ and Beeforth,²⁰ from a SU perspective, make attempts to educate decision-makers in what is entailed in user involvement. Barnes and Bowl,²¹ writing as academics, considered the development both of autonomous action by SUs and the way in which officially sponsored initiatives interacted with this and, in some cases, led to tensions between 'official' involvement initiatives and grassroots activity. Bowl,^{22,23} for example, found that consultation mechanisms designed to give mental health SUs a say in service planning and delivery in accordance with the 1990 provisions were little more than rubber-stamping exercises. Others have also explored the importance of collective action to enable those often regarded as incompetent to contribute to debate about services to have their say.²⁴

To return to Crossley,¹⁷ his argument has not gone uncontested even while the image of the disempowered psychiatric patient has been augmented and the idea of a new social movement consolidated. Rather his conceptualisations have been criticised from 'within' the movement. The Survivor History Group²⁵ sees more a grassroots movement, with ex-patients organising for themselves and by themselves. They are suspicious of the role both of the antipsychiatry movement and the large national charities, such as MIND and especially the National Schizophrenia Fellowship (still its registered name but known now as Rethink). The Survivor History Group takes the view that neither of these developments put patients at the centre of their activities and indeed that they sidelined the rapidly growing user movement in the 1980s and 1990s, although MIND extended help to Survivors Speak Out when it was forming. This was not without criticism from within the organisation.²⁶

By the early 2000s, perhaps as a result of the demise of initiatives such as the Mental Health Task Force User Group, national organisations, including Survivors Speak Out and the United Kingdom Advocacy Network, were on the wane. The Sainsbury Centre for Mental Health²⁷ undertook a large survey of the user movement in England and found a very large number of local user groups but a dearth of national activity. The local groups tended to be small in membership, poorly resourced and dependent on the will and energy of one or two individuals. However, they were involved with statutory authorities, who sometimes

provided funding and other resources in a consultative capacity or furnishing other information. These groups also provided mutual support for their members and a common activity was training mental health staff. Campaigning activities were infrequent, which marks this period off from the decade before it. There is an academic literature that has examined these user groups, their activities and their relationships to commissioners and providers, and we will look at this in *Chapter 3* (see *User-led organisations*) and in *Chapter 4*.

As part of the work of the Sainsbury Centre for Mental Health, one of the current authors (DR) interviewed all but one of the SUs who were part of the National Service Framework Internal Reference Group. We have already noted that this document declared user involvement to be a core principle. This did not seem to work in the formulation of the Framework itself. With one exception, the SU members said they would never do national involvement work again and four resigned before the work of the Internal Reference Group (IRG) was complete. In particular, SUs from black and minority ethnic (BME) communities stated that they faced racism from white SUs and patronising attitudes from professionals from their own communities. It was not surprising then that the Sainsbury Centre for Mental Health survey found the SU/survivor movement to be made up almost exclusively of small local groups at that point in time. This localism may extend to mental health SUI in more generic groups, such as LINKS. The exception was radical new understandings relating to certain experiences, such as hearing voices or self-harm.

Wallcraft *et al.*²⁷ concluded their report with the recommendation that a new national user group should be established. This now has the form of NSUN, which became an independent charity, with core funding, in 2012. NSUN works together with the larger mental health charities and also provides advice and assistance to local user groups especially on how to gain charitable status. They have the ear of government, having decided that being a critical friend is better than being out in the cold. This does not commend them to all who identify as mental health SUs and survivors. However, they are now a recognised part of the landscape and it seems they can speak the corporate language that the IRG SU members eschewed, something that is both critical to the success of the user movement and difficult to accomplish as we shall see.

Organisational theory

Organisational culture has been identified as key to understanding the responses to, and impacts of, user involvement in the NHS and social care. Organisational culture encompasses the attitudes, beliefs and behaviour of managers, both individually and in groups, when they interact with groups and individuals outside their organisation.^{28,29} Although user involvement is government policy and, thus, the policy of every trust and other health organisations such as PCTs and now CCGs, this does not tell us how organisations actually behave or how structures may or may not be permeable to new ideas. Barnes and Prior³⁰ explore different ways in which both front-line workers and SUs may resist and frustrate policy objectives. Rose *et al.*³¹ concluded that open hierarchies and weak power structures were most conducive to successful user involvement. Parkes³² identified both organisational and professional strategies of resistance to the voices of services users that suggested it was less a question of overt power being exercised, but rather 'hidden, almost tentative' dissent (p. 181). A particular difficulty in mental health is that both front-line staff and managers may dilute the impacts of user involvement activity by 'pathologising' the individuals involved and indicating that certain expressions of emotion are a sign of relapse of mental illness.³³ There would appear to be certain contexts in which 'authentic experience' is prized by organisations, and others where it is considered inappropriate to institutional and behavioural rules and norms. The significance of the latter is the focus of work on the relevance of new institutional theory to new forms of participative policy-making and service development in a range of policy contexts.^{34,35}

In this context, the argument by Harrison *et al.*³⁶ is pertinent. From interviews with managers, they found that user groups had apparently been accepted as stakeholders but this acceptance may be qualified, for example, by criticisms of their 'unrepresentativeness' or 'chaotic organisational style'. Harrison *et al.*³⁶ argue that managers emphasise their acceptance of user groups' positions when the groups endorse their decisions and emphasise their qualification of this acceptance when there are disagreements either

between managers and user groups or between different managers. They describe this as 'playing the user card'. This work is now 15 years old and in this report we will consider whether such moves still hold sway or whether they have given way to other organisational strategies for dealing with ULOs including, for example, bringing user involvement 'in house'.

Rose *et al.*³¹ also discuss how far Iles and Sutherland's³⁷ model of external factors in organisational change can apply to mental health SUs. The importance of the autonomous user group has been recognised, but at the same time it is difficult to see SUs as 'external' stakeholders because they are so embedded in the mental health system. This is even more the case with the advent of Community Treatment Orders (CTOs) in 2007, with large numbers of people now 'living in the community' but under very strict restrictions from mental health services. It must also be considered that some mental health SUs, including those under CTOs, have no chance of 'exit' (just walking away from services) as a means of expressing their views as they are using services under compulsion. Thus, 'voice' is of particular importance, as we have said. And the power to exercise voice can be considerably enhanced by opportunities to share experiences with others, and to receive support and validation from others with similar experiences of mental health difficulties. It is all too easy to see this group as mere bearers of pathology, a view that immediately undermines a partnership approach to service change. More pragmatically, most people with long-term conditions belong to older age groups but people with enduring mental health problems tend to be younger and, therefore, require a range of different services to live independently in the community. People with mental health problems then constitute a 'limit case' for NHS and social care managers. Successful user involvement for this group is important in itself but also has lessons for other users of public services.

In terms of the traditional model for organisational change, which focuses on external stakeholders, a further issue is that many trusts have now brought user involvement 'in house', starting with the Patient Advice and Liaison Service (PALS) and then appointing PPI leads, whose role is to monitor the 'patient experience'. Often there is an uneasy relation between such roles and existing autonomous groups, as we shall see throughout this report.

The emphasis on cultural change, and promoting democracy and representation, however, mirrors other work^{22,23} in relation to the *National Health Service and Community Care Act 1990*. Iles and Sutherland³⁷ stress that not all members of a culture need to be compliant with proposed changes for them to come about. The problem we have is that currently organisational culture in the NHS and social care is changing so rapidly that it is difficult for SUs and their organisations to know where to intervene in order to optimise beneficial change. Indeed, it is difficult for purchasers and providers as well, not all of whom are content with the changing organisational climate. We explore this further in *Chapter 4*.

Although many have identified the problem of pathologising SU behaviour, or the dominance of organisational norms that render it inappropriate, there remains an issue of involving people who episodically cannot contribute. Indeed, not all of this is specific to mental health. Small organisations of health and social care recipients often find the burden of work expected of them to outstrip their resources, as those in positions of power in organisations do not seem to appreciate that some SUs are involved in a voluntary capacity, may have jobs or other responsibilities, and must juggle their time to fit in with organisational demands. Much of the burden often falls on the shoulders of a few committed individuals who experience great pressure. In a mental health context, this can lead to people becoming unwell for periods of time and we shall see in our work on user governors that this is not always planned for. At the worst, if leaders experience an episode of poor mental health, an organisation can collapse. Sustainability is a major issue. There is then a lesson for decision-makers that is quite complex. This is to avoid undue pathologisation of behaviour that is an expression of grassroots experience while at the same time to put in place structures to deal with the possibility of people being out of action for periods.

Origins of this study

The current investigation has its origins in a clinical research group funded by the Mental Health Research Network (MHRN), which met in 2009–10. It builds on two literature reviews funded by the Service Delivery Organisation (SDO) programme.^{31,38} Rose *et al.* reviewed the literature on user involvement in change management in a mental health context and Crawford *et al.*^{31,38} did this generically. The study reported here represents primary research that builds on the findings of the literature reviews and takes account of developments in user involvement in service delivery that has occurred since we wrote them. Our focus in this study is on user involvement in mental health services, highlighting, in particular, changing patterns and mechanisms for involvement that have come about as a result both of acceptance of involvement as official policy within the NHS, and changing models of service delivery. We conducted the study in three NHS FTs: two metropolitan and one rural that also had a small urban population.

A major finding of the literature reviews was a lack of investigation of *outcomes*. The majority of papers were about process and offered little evidence on specific outcomes or impacts. So, following from the literature review, Rose *et al.*³⁹ conducted an empirical pilot study of user involvement in changing mental health services in two London boroughs. Respondents thought user involvement did have some impact and there was no difference in this study between the perceptions of the impact as between ‘activists’ (defined as participants in user groups) and ‘non-activists’, showing that user involvement could be important for ‘ordinary’ SUs. Unusually, Pilgrim and Waldron⁴⁰ did study whether or not a user group had achieved its goals. However, they did not study process and our argument is that outcomes and process must be studied in tandem. The first task of this study then was an investigation of the impact of user involvement on service development from the perspectives of SUs themselves and also front-line staff. This took the form of a survey and is reported in *Chapter 3* (see *Phase 1: impact of user involvement – survey results*).

We also sought to look in detail at the functioning of traditional ULOs in a modern context. With immense organisational change, how do traditional ULOs fare? In particular, are they effective in achieving their own goals and in effecting change in a direction set by them? To answer these questions we conducted an ethnography over an average of a 1-year period with six ULOs – two from each site. Much has been written about ULOs in the 1990s and 2000s, but what does the current organisational climate mean for their internal dynamics and interactions with purchasers and providers? The ethnography is a topic of *Chapter 3* (see *User-led organisations*).

We suggested above that there may be a move taking place from collective forms of SUI (of which ULOs are one) to more individual forms. One such is the possibility, with the development of FTs, for SUs to be members and governors of FTs. This is a ‘top-down’ development. Nowhere can we find evidence that SUs asked for this. However, this does not mean it is unwelcome or cannot benefit both user governors themselves and their organisations. In our three sites, we observed Council of Governor meetings with user governors present, observed subcommittees, ran focus groups with user governors and interviewed each council chairperson. We wanted to know how much ‘voice’ the user governors had in organisational change in the trusts, as well as how they saw themselves in terms of ‘representation’ of a constituency or mandate to a local group. This part of the work is covered in *Chapter 3* (see *Service user governors*) of the report.

Having patients or SUs on a FT board represents potential influence at a high organisational level. At the other end of the scale is influence over one’s own care. This is not new. In 1995 the government’s *Building Bridges*⁴¹ stated that SUs should have influence over their own Care Programme Approach, especially drawing up care plans and arranging reviews. The evidence is that this was not happening then,⁴² and, even with a review of Care Programme Approach in 2008, is not happening now.⁴³ However, as we saw above, something much more radical is now being proposed and that is that SUs should be given their own budgets, for both health and social care, so they can personally commission the care of their choice. In our proposal for this study, we said we would examine personalisation through focus groups with people who held personal budgets. There are certainly things to be said about this

development, which will be taken up in *Chapter 3* (see *Personalisation*). However, we can alert the reader now to the fact that people in receipt of personal budgets in our three sites were extremely difficult to find. This was not for want of effort and we conclude that, in mental health at least, this innovation bewilders staff and SUs alike.

When we planned this study we were acutely aware that we would be working in a complex, dynamic and constantly changing environment. It is safe to say that the changes we observed and in which our participants had to conduct their involvement activities, or respond to these, was even more complex than anticipated. We have therefore devoted a section of the *Discussion* to considering this context and how it impacted on mental health SUs, their organisations and decision-makers during the course of the work.

In the last analysis, this report is for managers as much as it is for SUs and front-line staff. We accessed the views of senior managers in two ways. At the beginning of the study, we held interviews with eight senior staff in each trust (and including some involved in the emergent CCGs) to find out their opinions on SUI, the forms that it took and had taken historically in their trust, and especially what they thought the impacts had been, both positive and negative. Second, we held a deliberative workshop at the end of the study for the same managers we had interviewed at the start. Here we presented them with our main findings and asked for their views. This was more than a dissemination event as we were asking them actively to help us interpret the information we had collected. We changed some of our own interpretations as a result. The interviews are detailed in *Chapter 3* (see *Managers', commissioners' and clinicians views on user involvement*) and are drawn on in other sections of the report, as are the interpretations offered in the workshop.

Patient and public involvement

Patient and public involvement has been central to this research project from inception, to execution, to dissemination. The clinical research group from which it arose, and which designed it, comprised SU researchers, social science academics, clinical academics and service providers. Thus, it was collaborative and the role of SU researchers was strong from the beginning. In addition, a penultimate draft of the protocol was sent to five SUs with different experiences of research to make sure that the study would capture what is important about SUI in service planning and delivery from the perspective of those involved. This commitment to PPI in research has been continued in the project itself. The chief investigator is a SU researcher who additionally has long experience in the SU movement in mental health as well as the wider disability movement. There is SU representation among the research assistants, including again, experience in the wider disability movement. There is also a SU researcher on the steering group, who also brings a wider cross-disability perspective. This perspective has been very important for the work on personalisation. However, as specifically mental health SUs, team members know at first hand that the discourse and practice of psychiatry can be problematic in terms of diagnosis and therapeutics, and also that mental health services can be coercive. As such, there is much 'insider knowledge' that allows us to frame questions in a way that is most relevant to our participants. In terms of data collection and interpretation, there is, of course, an issue about whether or not this makes any difference so as to augment the quality and relevance of the work. The literature is ambivalent about whether or not SU researchers obtain different data to conventional mental health researchers for quantitative methods (Rose *et al.*⁴² suggesting that they do, but Rose *et al.*⁴⁴ suggesting no difference). However, for qualitative methods there is evidence that SU researchers both collect and interpret data differently from conventional researchers, and in a way that is more in tune with the priorities of SUs themselves.⁴⁵ The bulk of this study uses qualitative methods and this implies that we were able to elucidate the dimensions of user involvement in mental health that are important to our participants. Earlier in this chapter we saw that the mental health SU movement in earlier days often counted some academics as 'allies'. These allies are represented on the team, as their work is represented in our project. They have conceptualised the position of mental health SUs in the changing landscape of the last 30 years, as well as conducting empirical work. So this study does not just involve patients and the public in minor roles in the research

team, or even just as steering group members, as is often the case. PPI is central to its empirical work and also its theoretical contribution. In terms of PPI in research this study is collaborative and could indeed be said to be SU researcher led.

Aims and objectives

The overall aim of this project is to examine how managers and key decision-makers have responded to user involvement activities in mental health and to identify how they facilitate or impede effective patient and public involvement. This is a novel aim, as there is a great paucity of literature on what the impacts of user involvement activities have been, especially in terms of the responses of key decision-makers. Our secondary main aim is to look at the changing face of user involvement in mental health where more 'traditional' models may be giving way to more of a focus on individual involvement, for example in the area of personalisation. We have linked this overall research question with the following objectives and specific research questions:

1. What have been the impacts of user involvement in mental health in terms of service development, delivery, commissioning and personal benefit to users? We have the same research question for front-line staff.
2. How do managers and other key decision-makers respond when ULOs approach them seeking change?
3. Moving to a more individual level of user involvement, what is the role played by user governors on trust boards and how do key decision-makers on the boards respond to them?
4. What are the implications of the move to 'personalisation' in both health and social care, specifically in terms of the role of ULOs in brokerage and care planning?
5. What are the underlying assumptions, beliefs and values held by senior managers about the benefits and drawbacks of user involvement in mental health and how do they individually and collectively respond to, facilitate or impede this?

Chapter 2 Methods

The study uses mixed methods, this approach having been argued as most pertinent to the study of organisational dynamics and change.^{46,47} Ferlie²⁸ argues that research methods in organisational studies have undergone a 'paradigm shift' in recent years moving from the more positivist to the more interpretivist. He argues that it is possible to deploy a range of methods within a single study, each being appropriate to the research question. We used surveys, in-depth qualitative interviews, ethnography, focus groups, case study designs and deliberative workshops as appropriate to the phase of the research.

Sample and setting

Different sampling strategies were used for different phases of the research, as will become clear below. In terms of settings, the study took place in three NHS FTs. Two of these were metropolitan (trusts A and B) and one was rural with a small urban population (trust C). All are FTs. They cover an area with over 9 million residents, of whom > 220,000 are estimated to be in contact with mental health services. The two metropolitan trusts service a population that is younger, more ethnically diverse and with greater mental health needs than other parts of the UK.⁴⁸ The sampling of the two metropolitan trusts is conceptual. Trust B is paying close attention to lay representation on the trust board, the object of our investigation in phase 2 – stage 2. Trust A is undergoing reconfiguration. As these two sites are urban, we selected a more rural site, as rurality may impact on the nature and outcomes of user involvement.

Phase 1: the impact of user involvement – survey

A cross-sectional survey of SUs and providers was conducted in the three mental health trusts. The targets of the study were people who use mental health services and front-line mental health professionals who work in these services. Fieldwork for the survey began in July 2011 and was completed in April 2012. A questionnaire with closed and open-ended questions was used to collect the responses of both SUs and front-line professionals. SUs were interviewed in person by members of the research team, and professionals were invited to participate using a self-completion online questionnaire.

The survey addressed the respondents' experiences of participating in user involvement initiatives, as well as their views about the impact of various forms of user involvement activity. During the initial phase of the interview respondents were screened for eligibility and verbal consent was sought before proceeding with the survey questions. Following informed consent, SU participants were provided with written information about the project and were encouraged to express themselves freely and independently when completing the questionnaire. Professionals were contacted by e-mail 1 week prior to the distribution of the electronic survey, giving them the opportunity to review the informational material and opt out of receiving the electronic questionnaire. Basic demographic information was collected, but no respondent could be identified.

Sample

We aimed to collect responses from 100 SUs and 42 front-line professionals [21 community psychiatric nurses (CPNs) and 21 social workers] per trust. Potential participants for the survey of SUs' views were identified by attending Community Mental Health Teams (CMHTs), outpatient clinics and local day centres. It was hoped that by identifying SUs through ordinary clinical contexts, such as waiting rooms and outpatient clinics, it would be possible to obtain the views of a representative sample of SUs.

The sampling frame for the survey of front-line mental health professionals was drawn up using data from the human resources departments of each trust. E-mails were sent to a random sample of mental health nurses and social workers asking them to complete an on-line survey. This was supplemented by visits to CMHTs in all three trusts. Social workers and community mental health nurses were approached in person and asked to complete a paper version of the questionnaire.

The numbers of front-line professionals interviewed were hypothesis driven and based on a power calculation. We predicted that social workers would be more influenced by SUI activities than nurses, and more likely to have directly participated in user involvement initiatives. There is support in the literature for this⁴⁹ and user involvement is a mandatory part of social work education. The sample size was based on the ability to test the hypothesis of a difference in mean outcome scores between two independent groups: social workers and CPNs. We therefore estimate the sample size to be able to detect a standardised effect size of 0.5, considered a medium effect size. To be able to detect at least this magnitude of a difference with 80% power at the 5% level of significance (two sided) we needed 63 participants in each group and this corresponds with 21 in each group per trust as given above.

Questionnaire design

The survey questionnaire was based on a core set of questions derived from reviews of literature conducted by Rose *et al.*³¹ and Crawford *et al.*³⁸ The survey design also built on the findings generated from the Rose *et al.*'s³⁹ user-led study investigating the perceptions of activist and non-activist SUs on the outcomes of user involvement.

Section 1 of the questionnaire contained a series of examples of user involvement activities and SUs were asked to identify forms of involvement, if any, in which they had participated. Based on a modified template of the SU questionnaire, section 1 of the professional survey also included a comprehensive list of user involvement activities. Professionals were asked to identify areas where they had direct experience of involving SUs.

Section 2 of the questionnaire consisted of a series of questions asking SUs and professionals about the impact of user involvement on various areas of service delivery. We used a six-point Likert scale to measure SU and staff perceptions about the level of impact SUI had within particular contexts of mental health service delivery.

Section 2 of the questionnaire also included a series of open-ended questions. Participants were asked to identify examples of both the positive and negative impact of user involvement activities, and could enter their responses by writing in the open-ended text box sections of the survey. Some respondents gave verbal responses, with a researcher writing down the answers in the relevant section of the questionnaire. In the concluding question of section 2 of the questionnaire, SU participants were asked whether or not they felt user involvement was beneficial to them personally. Professionals were asked if SUI was beneficial to SUs in general. The question listed three response options (yes, no, my views are mixed), followed by an open-ended section asking both sets of participants to further elaborate on their answers.

In section 3 of the questionnaire, SU participants were asked to provide additional details, including their age (in age bands), ethnicity and gender. SUs were asked additional information about their diagnosis and length of time that they had been in contact with mental health services. Mental health professionals were also asked about their professional background (social work, CPN) and length of employment within mental health services.

Data analysis

The analysis of the quantitative data involved calculating the frequency and distribution of survey responses. Levels of involvement in different activities were calculated. Descriptive statistics were also used to (1) assess the extent of participation in different types of user involvement activities and (2) determine the total proportion of SUs and staff who felt that involvement was having a positive impact. All quantitative data analysis was conducted using SPSS version 20 (SPSS Inc., Chicago, IL, USA). We used a binary logistic regression to examine factors associated with whether or not SUs and front-line professionals had been involved in user involvement activities. Diagnosis categories were omitted from the list of predictor variables owing to the low response rate associated with this question in the survey. The dichotomous dependent variable was calculated as the response given by professionals and SUs, to the question of whether or not they have had been involved in user involvement activity (yes/no). We used the 'Enter' method to perform a

standard regression analysis in which the relationship between explanatory variables and the main outcome is adjusted for the impact of all other variables in the model.

Open-ended sections of the questionnaire were analysed using the qualitative data analysis programme NVivo version 9 (QSR International, Warrington, UK). A thematic content analysis was used in the review of the data.⁵⁰ The primary researcher studied each of the participants' responses and identified themes emerging from the data. Following the completion of the initial thematic analysis all responses were reviewed and reassessed to achieve consistency and avoid discrepancies.

Phase 1: impact 2 – senior staff interviews

Sample

In order to explore what senior staff thought about the current state of SUI and the impact it was achieving, we undertook semistructured interviews with:

- three chief executive officers (CEOs)
- three consultant psychiatrists
- six staff involved in commissioning and contracts
- two senior managers with social care responsibilities and one lead on personalisation
- two senior clinical managers and one occupational therapy lead;
- five team leaders and one general manager for recovery teams.

The interviews were conducted in a place of the respondents' choosing, usually their place of work. The interviews were digitally recorded and transcribed.

Topic guide

The topic guide was based on previous work into SUI³⁴ informed by our knowledge of the configuration of SUI in the three trusts.

Analysis

In this analysis we considered the responses across the three trusts, highlighting any particular differences that emerged, but we did not undertake a trust-by-trust comparison.

Analysis was conducted using NVivo software. A coding frame was developed, drawing on previous research into user involvement and public participation (see Barnes *et al.*³⁴ and *Appendix 1*). This framework included both descriptive and analytical codes. For example, methods for involving SUs described by interviewees were coded descriptively (involvement in staff recruitment, user councils, etc.); analytical codes were used to capture the discourses that framed the way in which respondents spoke about user involvement – by reference to empowerment or consumerism, for example. Further codes were added based on initial readings of interview transcripts.

Phase 2

Phase 2 falls into three stages, all of them deploying qualitative methods. Stage 1 is an ethnography of ULOs. Stage 2 used qualitative methods to investigate user governors on FT boards and stage 3 took the form of focus groups with people in receipt of personal budgets.

Phase 2: stage 1 – user-led organisations

Design

This stage, based on research question 2, used an exploratory, multiple case study design,⁵¹ with a specific ethnographic framework. We aimed to look for both literal and theoretical replication.

Sample

We aimed to examine two ULOs per trust: one traditional and one more specific.

Data collection

We studied the ULOs 'in action' as they interacted both among themselves and with purchasers and providers. We asked each group to identify a key goal that the research might study. This might relate to an ongoing issue that the group is pursuing or involved in (e.g. service commissioning) or it may be a specific time-limited project (e.g. developing SU-led audit process). The aim was to focus on a live issue on which the group was engaged during the study period in order to follow through the process of action and dialogue as it happens, and to identify how change takes place and what is achieved during this period. Given the focus of the study, we encouraged the groups to identify goals that involved interaction with key decision-makers. We asked two group members to keep reflective diaries and record key events, who was involved, what their expectations and responses to specific events and interactions were, providing 'thick descriptions' which would enable analysis not only of what happened, but also of what factors were facilitating or acting as barriers to impact.⁵² Meetings with decision-makers during which critical events/issues were being negotiated were observed by a researcher. Internal meetings of the groups themselves, as they discussed their goals and the outcomes of meetings with decision-makers, were also observed. Towards the end of the ethnography, researchers undertook follow-up interviews with key informants. These interviews were digitally recorded and transcribed. We aimed for a 12-month period for the entire exercise, calculating that this should be enough time to identify outcomes and relations between users and managers. In this stage, we also asked group members how being part of a user group may have impacted on them personally, for example by developing new skills, confidence or widening their social network (although the opposite may be true if a disproportionate amount of work falls on the shoulders of key individuals). Using observation, fieldwork notes, reflective diaries and interviews allowed the triangulation of data and also ensured that the data were grounded in the experiences, reflections and perceptions of the participants.

Data analysis

The interviews were analysed adopting a thematic approach⁵⁰ supported by the qualitative software NVivo. We aimed to identify those moments when progress on the achievement of the identified goals moved forward or was impeded and what accounted for that. Interpretations of meetings relied on field notes which were analysed using ethnographic principles of 'thick description' and interpretation^{53,54} made possible by the combination of data collection methods described above. The analysis was inductive although it drew on what is already known about ULOs and the advantages and disadvantages of this form of organisation in mental health service development and delivery.

Phase 2: stage 2 – user governors on foundation trusts

With this phase, based on research question 3, we move towards a more 'individual' level of user involvement in mental health looking at mental health SUs as lay members of the three trust boards.

Sample

All three trusts are FTs and so are obliged to have both user members and user governors. Trust B had a complex system of subcommittees and trust C a rather weaker one. As trust B had developed its system of lay governance to a much greater extent than the other trusts, descriptive comparisons can be made.

Data collection

Data collection was by observation, focus groups and interview. Researchers observed the board of governors, which is the main meeting of all governors and took fieldwork notes. In trust B, subcommittees were observed in the same way and in trust C one pre-meeting of user governors was also observed. Additionally, a focus group of user governors was convened in each trust, focusing on what influence they believed they were able to exert, and this was digitally recorded and transcribed. Finally, the chairperson of the board of governors was interviewed and this interview too was recorded and transcribed.

Analysis

The analysis of this qualitative data was essentially the same as for stage 1. However, little is known about the influence user governors have on FTs, if any, and so this analysis was essentially inductive, although it did draw on the same analytic framework used in the interpretation of the senior staff interviews.

Phase 2: stage 3 – personalisation

We have seen in *Chapter 1* that government policy is that support for people with disabilities should move to a model of individual commissioning and this is known as personalisation. The aim of this stage was to see how this is proceeding from the point of view of recipients themselves.

Sample

Personalisation at the time of this research was mostly by means of individual budgets administered by local authorities. There are four local authorities in trust A, five in trust B and three in trust C. We aimed to carry out focus groups with people in receipt of individual budgets in at least two of the local authorities in each trust. Participants were accessed via gatekeepers, often staff who had participated in the senior staff interviews.

Data collection

Data collection was by means of focus groups, which highlighted assessment criteria [Fair Access to Care Services (FACS)], the amount of money allocated and what people spent it on, including restrictions on what they were permitted to spend it on. We were also interested to examine personalisation as a move to more individualised service provision and, so, included questions in the topic guide to see whether or not recipients ever ‘pooled’ their budgets in a form of collective provision.

Data analysis

As with SU governors, little is known about the perspectives of people receiving this kind of support, although we do know both that uptake is modest among mental health SUs and yet that when mental health SUs do access this form of provision it seems to have a beneficial impact on quality of life.⁷ We took this into account in the thematic analysis.⁵⁰ It is also known that local authorities utilise FACS differently and, so, this was be part of the analysis.

Phase 3: deliberative workshop with senior staff

Aim

We sought to enlist the help of senior staff in the interpretation of our findings. The deliberative workshop was more than a dissemination event, as we wished active involvement in the interpretation of the whole study. This is consistent with a main audience for the project being the community of NHS managers.

Sample

All senior staff who had participated in the qualitative interviews in phase 1 were invited to the half-day workshop, which was held on 1 March 2013 in the headquarters of trust B – this being a central location.

Data collection

The following presentations were made:

- Survey Results – Service Users and Front-line Staff.
- User-led Organisations.
- Complexity and Change.
- Barriers and Facilitators to Effective User Involvement.

This was followed by an open discussion, which was digitally recorded and transcribed.

Analysis

These data were not subject to systematic analysis but used to illuminate findings from throughout the study. This is consistent with the format of the workshop. User involvement is government policy, as we have seen, and hence it is the policy of all trusts. The issue is what happens at a more behavioural, attitudinal and organisational cultural level, and this is what the deliberative workshops aimed to uncover.²⁸ We sought to understand the 'subtext' of managers' discourse around user involvement in mental health while also making their own concerns central. We focused in particular on the kinds of issues raised by SUs in previous phases of the research, and investigated the way that senior managers conceptualised and responded to them.

Chapter 3 Results

Phase 1: impact of user involvement – survey results

Mental health user involvement has received increased emphasis since the *National Health Service and Community Care Act 1990*. Since its implementation, successive administrations have increased the emphasis of user involvement in service delivery and design. As a result of a series of policy initiatives, patients across all medical specialties are increasingly able to exercise choice and influence the services they receive. SUI in mental health services has become an integral aspect of service delivery and has developed across several areas including training, service development, management and research.^{31,38,55} Despite widespread promotion of a range of different approaches to incorporating the views of SUs in the development of health services, questions remain about the effectiveness of these different methods. In response to the relative lack of research on the impact of user involvement, Rose *et al.*^{31,39} highlighted the need for a further exploration of the outcomes of user involvement, instead of the ongoing focus on research examining user involvement processes and mechanisms. Rose *et al.*'s³⁹ research on user perceptions on the impact of user involvement initiatives looked at the views of 'activist' and 'non-activist' SUs. The research concluded that both groups of SUs, regardless of their level of engagement, felt that user involvement was having an important impact on services. The present study builds on the findings emerging from this research by looking at the views of a wider sample of SUs, as well as offering a more comprehensive analysis by including the perspectives of front-line mental health professionals.

Aims and setting

The overall aim of the survey was to ascertain the views of SU and front-line mental health professionals about the impact of SUI in various areas of service delivery. In addition, the survey was designed to examine SUI and provider awareness of different forms of user involvement and the extent to which SUs and professionals have been involved in these activities.

Results

Of 630 SUs who were asked to participate in the survey 302 (48%) agreed. Most participants ($n = 201$, 66.4%) were recruited from community mental health and recovery clinics (66.6%), with 86 (28.5%) recruited from day centres and 14 (4.6%) from community-based substance misuse services. A total of 438 professionals were invited to participate in the online survey, of whom 95 (21%) submitted a completed questionnaire. A further 48 members of staff were approached directly by a member of the research team and completed a paper version of the questionnaire.

Overall, 45.5% of the sample fell within the age group 35–49 years ($n = 132$). In terms of ethnicity, 64% of the respondents ($n = 191$) were from a white ethnic background, with 35.9% ($n = 107$) from BME backgrounds (including black British, Asian and other ethnic groups). In terms of contact with services, nearly half ($n = 142$) had been in contact for > 10 years. The full demographic figures, including frequencies means and percentages for the sampled population of SUs and professionals, are presented in *Table 1*.

Data on the number and proportion of SUs and staff who had been involved in one or more user involvement activity are presented in *Table 2a*. *Table 2b* shows the portion of patients and staff who had been involved in specific activities and had reported a positive impact of the area of user involvement they had experienced.

TABLE 1 Descriptive statistics of the study sample: SUs and professionals

		Trust							
		A		B		C		Total	
		<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>N</i>	%
SUs									
Age groups (years)	≤ 34	13	13.5	33	33.3	21	22.1	67	23.1
	35–49	50	52.1	38	38.4	44	46.3	132	45.5
	≥ 50	33	34.4	28	28.3	30	31.6	91	31.4
Gender	Male	69	69.7	65	65.7	43	43.0	177	59.4
	Female	30	30.3	34	34.3	57	57.0	121	40.6
Ethnicity	White	45	45	54	54.5	92	92.9	192	64.1
	BME	55	55	45	45.5	7	7.1	108	35.9
Length of time in contact with mental health services (years)	0–5	12	12.6	30	30.3	33	34.0	75	25.8
	6–10	29	30.5	23	23.2	22	22.7	74	25.4
	> 10	54	56.8	46	46.5	42	43.3	142	48.8
Professionals									
Age group (years)	≤ 34	9	19.6	7	14.9	4	8.5	20	14.3
	35–49	24	52.2	31	66.0	26	55.3	81	57.9
	≥ 50	13	28.3	9	19.1	17	36.2	39	27.9
Gender	Male	18	39.1	20	42.6	10	21.3	48	34.3
	Female	28	60.9	27	57.4	37	78.7	92	65.7
Ethnicity	White	32	71.1	26	60.5	42	91.3	100	74.6
	Non-white	13	28.9	17	39.5	4	8.7	34	25.4
Length of time working in mental health services (years)	0–5	5	10.9	5	10.6	2	4.3	12	8.6
	6–10	13	28.3	16	34.0	13	27.7	42	30.0
	> 10	28	60.9	26	55.3	32	68.1	86	61.4
Professional background	Social worker	23	50.0	24	49.0	24	50.0	71	49.7
	CPN	23	50.0	25	51.0	24	50.0	72	50.3

Results broken down by NHS trust.

TABLE 2a Descriptive statistics of the sampled population of SUs and professionals

	SU (N = 302)				Staff (N = 143)				Difference % 95% CI	
	Involved		Not involved		Involved		Not involved			
	n	%	n	%	n	%	n	%		
Age groups (years)										
≤ 34	32	23.7	35	22.6	13	16.2	7	11.7	-4.3 to 6.3	-1.9 to 10.3
35-49	62	45.9	70	45.2	44	55.0	37	61.7	-4.8 to 10.1	-7.4 to 17.2
≥ 50	41	30.4	50	32.3	23	28.8	16	26.7	-3.2 to 9.2	-3.6 to 13.4
Gender										
Male	88	64.2	89	55.3	27	33.8	21	35.0	-8.3 to 9	-5.3 to 13.7
Female	49	35.8	72	44.7	53	66.2	39	65.0	0.5 to 14.7	-3.3 to 22.8
Ethnicity										
White	80	58.8	111	58.5	63	79.7	37	67.3	1.4 to 19.2	4.8 to 31.6
BME	56	41.2	51	41.5	16	20.3	18	32.7	-5.1 to 8.4	-6.6 to 9.4
Time in contact/working with services? (years)										
0-5 years	25	18.7	50	31.8	5	6.2	7	11.7	2.7 to 13.8	-3.3 to 6.1
6-10	37	27.6	37	23.6	20	25.0	22	36.7	-5.6 to 5.6	-7.5 to 10.3
> 10	72	53.7	70	44.6	55	68.8	31	51.7	-7.1 to 8.4	4.4 to 29.2
Trust										
A	63	45.7	38	23.2	28	35.0	18	28.6	1.8 to 14.7	-2.2 to 16.2
B	47	34.1	53	32.3	19	23.8	30	47.6	-4.5 to 8.5	-1.8 to 17.2
C	28	20.3	73	44.5	33	41.2	15	23.8	8.6 to 21.6	3.3 to 21.9
Professional group										
Social worker	n/a				45	56.2	26	41.3		0.9 to 11.7
CPN	n/a				35	43.8	37	58.7		-4.8 to 6.2

n/a, not applicable.

TABLE 2b Areas of involvement and reports of positive impact

Area of involvement	SUs				Staff			
	No. involved	% involved	No. reporting positive impact	% reporting positive impact ^a	No. involved	% involved	No. reporting positive impact	% reporting positive impact ^a
Shaping day services	59	42.8	51	86.4	9	11.3	8	88.9
Shaping residential services	16	11.6	15	93.8	4	5.0	2	50.0
Changing inpatient wards	25	18.1	19	76.0	13	16.3	9	69.2
Recruitment of staff	18	13.0	14	77.8	27	33.8	23	85.2
Training staff	21	15.2	16	76.2	41	51.3	38	92.7
Managing services	16	11.6	13	81.3	4	5.0	3	75.0
Evaluating services	64	46.4	41	64.1	43	55.0	37	86.0
Researching services	22	15.9	15	68.2	13	16.3	12	92.3
Commissioning services	10	7.2	7	70.0	5	6.3	1	20.0

^a Denominator for calculating these percentages is the number who reported being involved in this type of user involvement activity.

Figure 1 shows the overall percentage of staff and SUs who had taken part in various forms of activity, with the overall levels of reported positive impact in each area. The statistics are presented as percentages of the total sample of SUs and staff, including those who had not taken part in the various forms of user involvement activity. Results about, and levels of, reported positive impact of user involvement differed across the three trusts. SU participants in the metropolitan trusts (trusts A and B) were more likely to report

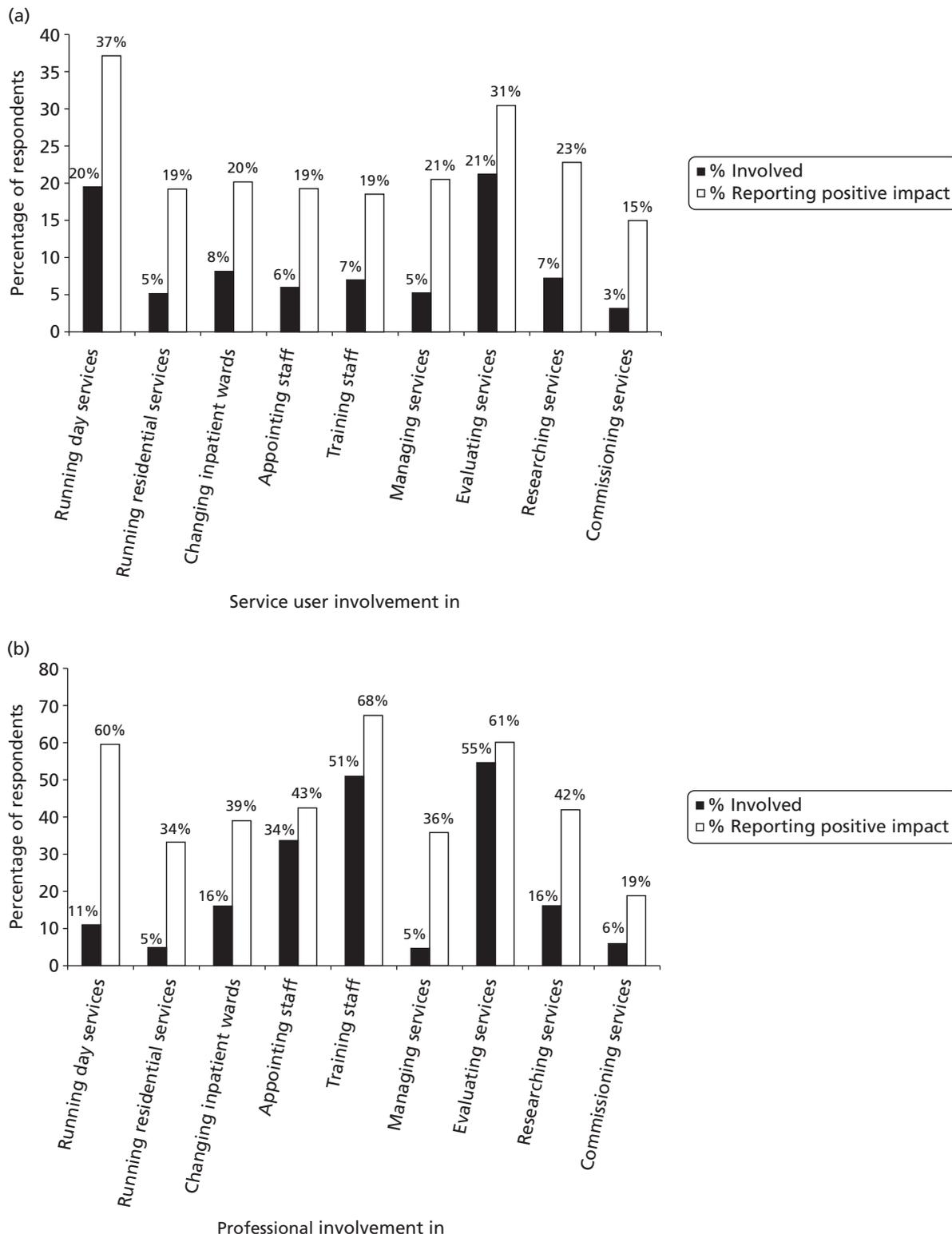


FIGURE 1 Levels of participation in user involvement and percentage of respondents reporting positive impact. Percentages of total sample of respondents: (a) SUs; and (b) professionals.

an overall positive impact of user involvement than participants in the rural trust (trust C). Their perceptions on the overall impact of user involvement across the three trusts are shown in *Figure 2*.

The results of the logistic regression examining factors which predict professional and SU participation in user involvement are shown in *Table 3*. The model shows the professionals in the age group 34 years and under are more likely than other age groups to be involved in SUI. White professionals were associated with a higher likelihood of being involved in user involvement activity. In terms of professional background, social work professionals were more likely to be involved in user involvement than CPNs. Increasing length of employment was a further predictor associated with SUI. Among SU participants, increasing length of contact with services and gender were associated with a higher likelihood of participating in involvement initiatives, with men being more likely to have experienced user involvement activities than women. In terms of ethnicity, SUs from BME backgrounds were more likely to be involved in user involvement initiatives than white SUs.

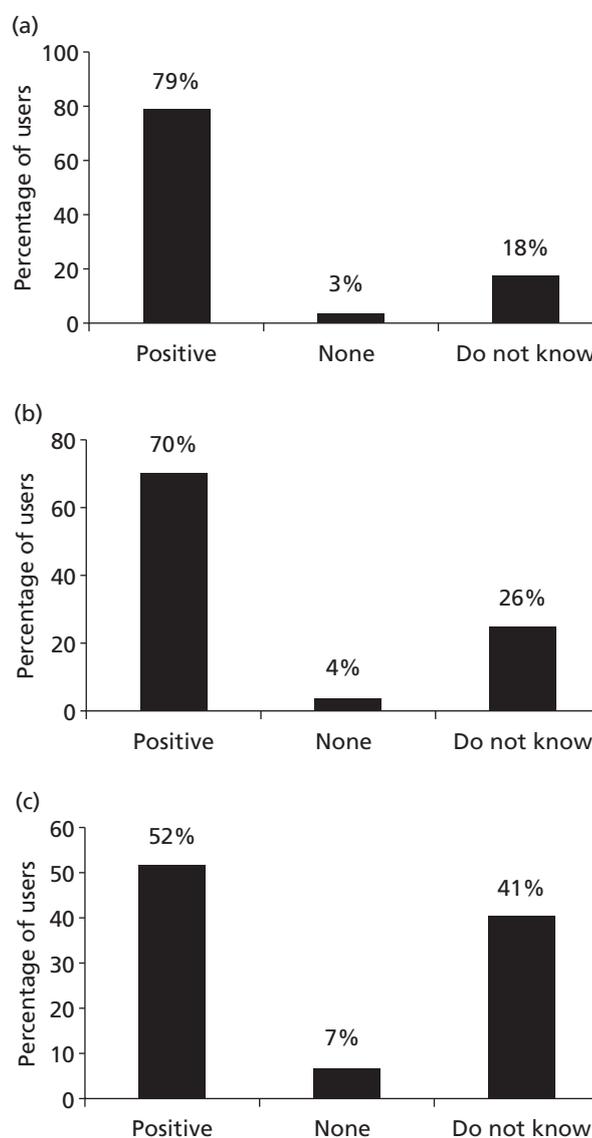


FIGURE 2 Service user perceptions of the overall impact of user involvement across the three NHS trusts. (a) Trust A; (b) trust B; and (c) trust C. Denominator for calculating these percentages is the number of respondents who reported being involved in this type of user involvement activity.

TABLE 3 Odds ratios associated with predictors of being involved in SUI

SUs				Professionals			
Characteristic	Odds ratio	95% CI		Characteristic	Odds ratio	95% CI	
		Lower	Upper			Lower	Upper
Age (years)				Age (years)			
≤ 34	1.00			≤ 34	1.00		
35–49	0.90	0.47	1.73	35–49	0.15	0.03	0.66
50–64	0.80	0.38	1.72	50–64	0.10	0.20	0.59
Gender				Gender			
Female	1.00			Female	1.00		
Male	1.55	0.94	2.55	Male	0.79	0.36	1.7
Ethnicity				Ethnicity			
White	1.00			White	1.00		
BME	1.95	1.18	3.21	BME	0.55	0.24	1.29
Time in contact (years)				Length employed (years)			
0–5	1.00			0–5	1.00		
6–10	2.09	1.04	4.19	6–10	3.25	0.59	17.8
> 10	2.48	1.28	4.81	> 10	11.1	1.77	69.9
Professional group				Professional group			
	n/a	n/a	n/a	CPN	1.0		
				Social worker	1.91	0.90	4.06

n/a, not applicable.

Benefits and disadvantages of service user involvement reported by service users and staff (qualitative analysis)

Table 4 shows advantages and disadvantages of SUI as reported by SUs and staff. The responses are from the open-ended sections of the questionnaire which elicited people's insights and views on the positive impacts of user involvement. As a part of the analysis, responses were qualitatively evaluated and categorised according to themes. In addition, the answers given by the survey participants were studied in order to identify core differences and similarities between the views of professionals and SU participants.

Having a say and being included

Professionals and SUs were generally in agreement about the benefits of user involvement. Both groups of respondents identified 'having a say and being included in decision making' as an important positive outcome; however, professionals seemed to frame this particular benefit in terms of *empowerment* and the ability to exercise choice and control. As two professional respondents noted:

A client on my caseload became actively involved as a service-user representative for our monthly team meeting. She found this to be empowering and confidence building. She felt that being able to put forward concerns raised at a separate service-user involvement meeting allowed herself and fellow users to be heard.

Feeling that they are being listened to, acknowledgement that they bring expertise, feeling more equal partners, feeling they may have been able to affect positive change.

TABLE 4a Benefits of user involvement reported by SUs and staff

SUs	<i>n</i>	Professionals	<i>n</i>
Having a say, being included in decision-making	35	SUs having a say, empowerment	26
Improvement in service design/delivery	25	Benefit to SU: therapeutic self-esteem recovery	16
Feeling listened to/opportunity to give opinion	20	Improvement in quality and type of services	15
Personal benefit: therapeutic, self-esteem, recovery	13	SUs feel listened to or valued	8
Opportunities for social interactions	11	SUs as source of knowledge expertise	7
Access to information about services/treatment, etc.	9	Access to information about treatment	3
Getting involved in groups and activities	7	Opportunities for professional development	3
Improvement in clinician–user relationship	7	Positive use of time, making a contribution	3
Opportunities for professional/skills development	5	Other	4
Other	4		

TABLE 4b Disadvantages of user involvement reported by SUs and staff

SUs	<i>n</i>	Professionals	<i>n</i>
Involvement tokenistic/does not lead to changes	11	SUs too negative, unconstructive criticism	12
Users not being able to participate owing to health	8	May be detrimental to mental health	9
SU input not seen as important	6	Those involved not representative	8
May be detrimental to person's mental health	5	SU input not seen as important	6
Other	3	Involvement tokenistic/does not lead to changes	6
		Unrealistic demands made by SUs	4
		Other	2

One professional made a particularly powerful statement about the importance of user involvement in the area of empowering people who use services:

It's empowering but more than that it's about tailoring services to the needs of those using them. Having a voice for those who have traditionally had none. Acknowledging the wholeness of someone. Just because someone has had difficulties in one aspect of their life does not make them less able to suggest improvements and increase understanding.

Unlike the professional respondents references to empowerment were rarely made in the answers given by SUs. The ability to exercise control and choice was articulated in more general terms as seen in the following responses:

I have a chance to say my piece. It affects the service I get. I'm glad they started using service users to impact services. I feel very involved in my treatment.

People were able to give opinion about day services and influence the trust in making decisions.

On a primary level I can have a say on how services are. It allows me to give my views on services. It allows me to have a say.

Overall, 35 SUs and 26 professionals identified 'having a say' as the important outcome and this was the response most frequently highlighted as a positive benefit of user involvement.

Improving services

A considerable number of SUs and professionals ($n = 25$; $n = 15$, respectively) described improvement to services as a significant positive outcome of user involvement initiatives. Professional respondents often referred to user involvement as a way making services more responsive to SU needs. SUs seemed to place a smaller emphasis on this, highlighting general service improvement and positive changes to the way services are delivered. Overall, the comments of SUs and staff about the role of user involvement in improving services were very similar, as seen in the examples below:

Involvement of service users in policy making helps to fill any gaps in the way services are delivered. There are still things that could be improved.

SU respondent

Service user involvement resulted in good changes in mental health services.

SU respondent

Service users have been involved in improving the service greatly through their feedback on the service and helping staff to acknowledge their needs in a more positive way.

Professional respondent

They have supported the team to better able to reflect with service users about the gaps between what services that they want and what services we provide.

Professional respondent

Services being more responsive to their needs. Services being provided for the benefit of service users rather than to suit staff. Being able to turn what could be a negative experience into a more positive one, particularly if things change as a result.

Professional respondent

User involvement as therapy

Professionals frequently identified therapeutic benefits associated with user involvement, as well as the positive impact of engagement activity on self-esteem and overall recovery ($n = 6$). Although less frequently than professionals, SUs identified similar personal benefits of user engagement ($n = 13$).

The responses given by professionals and SUs about the therapeutic benefits of user involvement were very similar, as seen in the following examples:

The whole experience of being involved and respected has helped me trust service providers and is good for my self-image and thus contributes positively to my recovery.

SU respondent

I have been a volunteer at (location) day centre for a year now (. . .) and this has had a huge influence on my confidence and a marked improvement in my mental well-being. A very good way to improve your well-being.

SU respondent

I have one person who has been volunteering at a day service cleaning this has given her structure to her day and given her purpose whilst she is recovering. This has also boosted her self-esteem.

Professional respondent

Having a work role is very important to someone's self esteem and confidence. I also believe that structure is very important when you are recovering. It is rewarding and therapeutic to be able to share lived experiences.

Professional respondent

Feeling listened to

A significant number of SUs ($n = 20$) identified feeling listened to and respected as an important outcome of user involvement. As seen in the examples below, participants who highlighted this particular benefit seemed to recognise the value of being acknowledged and respected by service providers:

It's empowering and beneficial to self-esteem and recovery to be listened to and respected. It helps us and service providers if they are aware of our insights and needs. Service users often know what best (despite their mental condition) is just from experience.

SU respondent

[I was] Able to say what I felt and happy they listened.

SU respondent

Professional respondents ($n = 8$) also highlighted the importance of giving SUs a sense of feeling listened to as an important effect of user involvement and gave similar descriptions as SU participants when describing it:

It gives them the idea of being listened and adhered to by the service/organisation.

Feeling that they are being listened to, acknowledgement that they bring expertise, feeling more equal partners, feeling they may have been able to affect positive change.

They feel listened to and part of the 'system' that is supporting them.

Opportunities for social interaction

In their comments on the benefits of user involvement, 11 SUs highlighted opportunities for social interaction as a positive aspect of user involvement. Only two professionals shared this belief. Examples of some of the SU responses are presented below:

It gives me the opportunity to talk to other people.

Access to housing, walking groups and activities such as cooking and interacting with friends.

Negative impact of user involvement

Both SU and professional respondents generated fewer ideas about the negative impact of user involvement. SUs most frequently referred to tokenism and failure of involvement initiatives to influence change as the main disadvantage of user involvement initiatives ($n = 11$). Comments on this subject included the following statements:

Users involved in order to 'rubber-stamp' decisions, i.e. paying lip service to user involvement.

I don't know what happens when I give my opinions. I give my opinions about the service and things don't change very much.

Very little is implemented. You tend to go with the flow.

In their comments on the negative impacts of user involvement, eight SUs observed that mental health issues may prevent people from taking part in user engagement activity. As demonstrated in the following examples, respondents highlighted the difficult challenge of managing a mental health condition while balancing commitments associated with user involvement tasks:

Because of your mental state you are not able to catch up with the work speed.

Mixed wards, not able to feed back about this, but opportunity was there. Would have wanted to give feedback but unable at the time due to illness.

A number of SUs ($n = 6$) commented on the relatively low status of SU input within mental health service. As one SU observes:

In my experience both here and other places service users opinions don't really matter. It's all about what the staff wants or think is right.

Service users also highlighted the negative impact of user involvement on the health of those of those who become involved ($n = 5$). There was a general recognition among these respondents that commitment to user engagement initiatives can be associated with significant pressure and stress:

Consultation process re. future of day services led to stress and possible hospital stay.

For some people the experience might be too much and the experience might result it them going back to hospital.

The uncertainty that the suggestion of changes brings can be quite destabilising to people with mental health issues.

Not being listened to and no positive constructive changes made which affect me in a negative way.

Professionals highlighted the issue of overly negative and unconstructive criticism from campaigners as a negative an outcome of user engagement initiatives, with 12 respondents highlighting this as a problem:

Generalised criticism of all social workers in a training session not dealt with in a reflective way but as an opportunity to have a go.

On one occasion it was quite disruptive as the service-user was extremely negative . . .

Sometimes at events with clients it can be a challenge for clients to voice appropriate opinions.

Used to be quite an aggressive aspect to service user involvement . . .

Similarly to SUs, professionals highlighted the issue of the negative impact user involvement may have on the health and self-esteem of those who become involved ($n = 9$):

Patient dropped out of peer support volunteer scheme which resulted in a negative impact on his self-esteem.

One needs to be selective when involving service users. Some service users thrive and embrace experience, whereas for some it is more stressful and can have a negative impact on their self esteem.

Professionals ($n = 8$) also identified the issue of 'representativeness' of individual SUs who become involved in shaping services. They questioned the rationale of identifying people to represent the wider population of SUs. Comments included:

Service user campaigns regarding services delivered may sometimes represent only a small service user demographic, i.e. those currently well, articulate, empowered, and perhaps those from a long background of MH care which doesn't necessarily reflect the views of today's newer service users.

There are often the same SUs some of whom have not been known to services for many years.

Sometimes service users champion their own cause and things become too focused on them.

Tokenistic practices and involvement initiatives that do not lead to change were identified by six professionals as a significant disadvantage of SUI. Comments included:

Service user involvement is often tokenistic, particularly when service users are consulted in making decisions about changes. More often than not consultations take place after important decisions about restructuring and reorganisation have already been made. Service users are asked about their opinion regarding these changes however they have little power to veto or change any decisions. In this current financial climate decisions are made quickly and 'consultations' are often rushed and retrospective.

As mentioned above I am not sure the users involved in the changes felt that they had any influence and that it was just a fait accompli.

When it's tokenistic and service users are given questionnaires and/or asked for their opinions on the service but receive no feedback and/or action plan relating to this.

Professional respondents also noted that user involvement may not be seen as important within mental health services ($n = 6$):

I can think of times when they have been asked about closing inpatient beds and I think their input has been ignored.

I cannot think of any input a service user has given that management have either listened to or acted on. Management and those involved with commissioning do not in my experience listen to service users.

Four professionals felt that user involvement initiatives may give a platform to SUs who make unrealistic and unreasonable demands that are unlikely to be satisfied.

The only negative impact I have experienced within my current service, is service users who (. . .) criticise from a point of view of unrealistic sense of entitlement to health and social care.

Demands made of service that is unrealistic.

Discussion

Of the 302 surveyed SUs, 138 (46%) reported having been involved in some form of user involvement work. Participation levels among professionals were similarly high with 55% of the 143 mental health workers reporting experience in at least one form of user engagement activity.

Participants who had taken part in user involvement work were likely to report a positive impact of the type of user involvement activity they had experienced. With a significant proportion of the sample recruited from community day centres, SU participants were most likely to report a positive impact of user

involvement in running day services. SUs were also likely to have participated in service evaluation and providing feedback about mental health services. This is not a surprise. As highlighted by Beresford,⁵⁶ SUI in this area has become 'significant and widespread' within health and social care, with funding providers and service commissioners emphasising the need for evidence that includes SU perspectives. However, this involvement has not been documented before.

Mental health workers were most likely to have direct experience of user involvement in training, a finding which is reflected in other studies highlighting the mainstream position of user involvement in professional education and training.^{55,57-59} A significant number of professionals had experience in involving SUs in service evaluation, although they were more likely than SUs to report a positive impact of this form of engagement. This is not surprising, as the results of evaluation initiatives – such as the national patient survey – are rarely fed back to patients, and professionals may be more aware of the outcomes of service improvement initiatives. Both SUs and professionals were least likely to have experience in the area of commissioning services.

The results of our survey mirror the findings of Kent and Read,⁴⁹ which showed that most mental health professionals viewed SUI positively. Kent and Read's study highlighted that professionals from psychosocial backgrounds were more likely to predict and associate benefits with user involvement than professionals with a more biological/medical background. Our analysis has shown that both groups of professionals were highly positive about SUI; however, social workers were more likely to have direct experience of user involvement activity (see *Table 3*).

Strengths and limitations

An important strength of the current study lies in its broad perspectives on SUI and the diverse range of user involvement mechanisms covered in the study. The structure of the questionnaire allowed for a measurement of the levels of participation in user involvement, as well as an overview of people's perceptions on the extent to which various initiatives were having a positive impact. Furthermore, participants were able to elaborate on their positive and negative experiences associated with user involvement. The inclusion of professionals, including social work and psychiatric nursing practitioners, added further depth to the study by encompassing multiple viewpoints on the subject, ensuring greater confidence in conclusions drawn from each group of respondents. A further strength of the study was the sampling method. SUs were recruited from ordinary clinical contexts, including community mental health clinics, day centres and community-based substance misuse services. All participants were recruited and interviewed in person by a member of the research team, with the focus being to collate a representative sample of SUs from individuals attending mental health services.

The survey has some important limitations. Although SUs were asked about their experience of SUI in the various areas of user involvement activity, the survey did not address the level of experience of SUs. There was a high degree of variation in the interpretation given by SUs about the areas of user involvement covered in the survey. For example, many, although not all, of those who reported experience of user involvement in running day services had not participated in the management of high-level decision-making within such services but had contributed in other ways, such as volunteering or had participated in organising groups and activities. Similarly, many of those who reported being involved in service evaluation had simply filled in a questionnaire or submitted a feedback form. However, regardless of the level of SUI, SUs were optimistic about the positive impact of their engagement in user involvement activity. Nevertheless, it must be stressed that our results are of SUs' *perceptions* of impact. In the chapters to follow we look at impact in practice.

Another limitation of the study is the possible response bias of participants, who may have been compelled to give 'morally right' responses to questions about user involvement. A further limitation relates to the fact that those responding to the survey were self-selecting and may have had previous engagement with the subject. People with an interest in service use involvement or those with a positive experience of involvement may have been both more likely to participate and more likely to express

positive views than those with limited experience or interest in the subject. Despite these possible limitations, efforts were made by the research team to include comments (both positive and negative) from those who had not been involved in SU engagement activities.

The poor response rate to the online survey targeting mental health professionals was a further limitation, as we did not know if those who responded to the survey were representative of those who did not. Nonetheless, their views about factors that promote and hinder user involvement provide valuable insights into the experiences of front-line staff working in NHS mental health services.

Conclusions

This part of our study set out to determine the overall levels of SUI among professionals and SUs and ascertain their views on the impact of SU engagement in various areas of service delivery. The findings have shown that there is a high level of participation in SUI activity and a general endorsement that involvement has a positive impact. The percentage of SUs and professionals who reported positive outcomes from activities they have been involved with was high, regardless of the type of activity they had experienced and their level of engagement in user involvement work. These findings provide an important context for the more in-depth qualitative work that constituted the next phases of the investigation.

Managers', team leaders', commissioners' and clinicians' views on user involvement

Introduction

As we explore later (see *Impact*, below) the context in which the interviews took place impacted on the way interviewees were thinking about user involvement and its place within mental health services. There was considerable uncertainty about the changing environment for mental health services. Early shifts towards CCGs were starting to happen, although there was little direct experience of how this would work in practice. Similarly, the introduction of personal budgets in relation to social care and, to a lesser extent, health care was anticipated to affect at least some SUs. Payment by Results was starting to have an impact, while the recovery agenda was quite well established in some places and was clearly shaping thinking. There was a general view that user involvement was an established part of the landscape in a way that it had not been 20 years before. However, the impact of financial cuts was a source of considerable uncertainty about the future.

Talking about service users

Service user involvement reflects a shift in the nature of the relationship between those working within mental health services and those with lived experience of mental illness. So we considered how interviewees spoke about SUs and what that suggested about the nature of this relationship. One team leader noted that it was 'them and us' when they first started work as a mental health nurse. Has this changed? We did not ask people directly how they viewed SUs, but rather coded responses in which they talked about SUs generally or through specific examples.

Two people resisted the term 'SUs', emphasising the importance of talking about 'people', and in one case people who could be 'you' and 'I'. This 'normalising' perspective was also evident in the enthusiastic discussion by three interviewees (two from trust C, one from trust B) of the impact of the recovery approach:

Early on in my training that was the central kind of philosophy . . . recovery philosophy, that people could do their own thing given resources and materials.

Team leader

It was also evident in others' discussions of opportunities for SUs to become employees, and the recognition that some employees of mental health services also used services. One talked of taking an approach based in fostering independence in order to make yourself 'redundant'. There was a recognition that some SUs became very expert about their own symptoms and come to their interactions with service providers having done research into potential treatments.

But comments that located SUs as 'patients', as people whose lives were disrupted and difficult, and/or by reference to their diagnosis and stage within their illness were more frequent. Such comments identified:

- The difficulties that those who are currently inpatients can find in expressing negative views about the way they are treated.
- The difficulties staff can experience in accessing people as 'patients' rather than as members of user groups.
- The reluctance of some clinicians to recognise patients as people who should be involved in decisions.
- The reluctance that may be felt by those experiencing disruption in their lives resulting from their illness to face anxieties associated with involvement in service change.
- A lack of capacity of those who are excluded and disempowered for ongoing involvement.
- Stresses associated with managing personal budgets.
- The need to recognise that enabling someone to take part in decision-making requires an ongoing relationship and a preparedness to take time.
- The impact of involving people with different diagnoses on the dynamics of group activities.
- The likelihood that those who are 'high functioning' will have less time for user involvement than others.
- Providers' fears about SUs' access to senior managers when their ideas and responses may be bizarre.

In addition to ways of speaking about SUs in general, interviewees also talked about those who might be considered 'activists' and others who have taken part in involvement initiatives. This reflected different assumptions and understandings of how SUI can be experienced and developed. It is also a factor influencing the likelihood of impact – assessments that those taking part are 'unrepresentative' or 'unreliable' can act to limit the seriousness with which users' contributions are received.

Some interviewees highlighted the significance of an emotional engagement motivating involvement, and the emotions that can be generated within involvement contexts. Some addressed this in terms of a perceived need to 'manage' emotions, either by training people *not* to express anger or by recognising that such involvement can generate anxiety by exposing people to decisions such as cutting budgets. They suggested that there is a need to explore rationales together and work to sustain relationships in order to reduce anger. One person emphasised the need for providers to look at the way they work and the mistakes they make in order to make it easier for SUs to remain involved.

Related comments suggested that it is experiences of bad treatment that often motivate involvement and that users of mental health services may be angrier than users of other health services – in part, as we have suggested, because of the potential and actual experience of compulsory detention. This could be framed as being 'passionate about a cause' or as having an 'axe to grind'. For example:

I don't mean to sound critical but there are times where you have to be very mindful that an individual doesn't hijack the forum for their agenda which has quite often been the case and they are there promoting their own individual agenda which isn't necessarily the more lateral experience of other people.

Team leader

And this was linked to what are considered acceptable and unacceptable forms of behaviour in the context of the institutional norms that are often assumed to determine appropriateness:

I think somebody who is very passionate about their own experience and still feeling emotional about it, you can have an understanding of it. There is always a time and a place, and as I say sometimes my experience has been that the timing isn't always appropriate for that person to raise those issues.

Team leader

Emotional responses defined as bad behaviour were also explained in terms of symptoms of mental illness and by frustration with the process of involvement. Responses included suggesting that 'opinions need to be left at the door' of involvement initiatives; service managers needed to pick people to take part who were comfortable dealing with opposing views; and, rather differently, there was a need for providers to learn from the emotional inputs of SUs.

In contrast with the suggestion that anger motivated participation, there was also a view that some users were unable to contemplate service changes because they had become too attached to existing ways of doing things. Here it was attachment rather than opposition to services that was considered to produce unhelpful resistance to discussions about change.

The need for support and training for users who become involved was discussed by some interviewees. This reflected a variety of perspectives. There was a common view that it was not helpful to expect individuals to be able to speak on behalf of users in general and to be effective as a 'lone voice' in the context of a large organisation. Thus, these interviewees spoke of 'support' in terms of the value of working with groups who could both bounce ideas around and offer a collective perspective, rather than 'training' for individual users to be more effective in taking part. There was recognition that some user groups can offer support to other users and some have systems to 'cover' when people may be unwell. Offering support to new or more 'fragile' groups to enable them to operate in this way can thus be useful.

Others did talk about training to enable users to be more effective in taking part in official forums. This was linked both to the need for 'specialist' or 'technical' knowledge, and to prevent what was referred to as a 'destructive' 'unleashing' of anger. Specialist training – relating to recruitment processes, research, commissioning and technical treatment issues – was identified. And for the following interviewee this was a means by which to ensure greater equality between SUs and workers:

... but actually you want someone that has the skills and training to do it, and if they haven't then thinking what mechanisms as an organisation do we need to put in place to make sure people are skilled up ... you want people who have skills, so when they come in they come in based as equals into that relationship, they are actually coming in with skills but they just so happen to use services in some way ...

Team manager

The context for involvement was seen to affect whether involved users should be both drawing on and recounting their own experiences, or reflecting a broader user perspective. Involvement in commissioning was seen as requiring a capacity to go beyond personal issues relating to a specific diagnosis. In contrast, SUs contributing to student training about the *Mental Health Act* were seen to have much to offer through recounting personal experiences of being sectioned. In this instance, support for those telling what can be difficult stories was considered important.

One person linked a capacity to contribute with the stage and severity of illness. This team leader suggested that 'former' SUs may be a more reliable source of input than that coming from those on current case loads who were going through crisis. The contribution of people who have been discharged who are prepared to come back to take part in user councils on hospital wards was also valued.

Other comments emphasised the commitment and expertise of involved SUs. Specific examples were offered, such as one person who had taken a lead in a successful campaign to provide a crisis house with strong SUI in its running. Many interviewees recognised that there are core groups of committed people who put in a lot of work and are very knowledgeable. Often this is unpaid and can put a considerable strain on them.

Commitment was sometimes linked with expertise – that related not only to experience in service use and in living with mental illness, but experience in the process of being involved. And a distinction was made between established user groups that one person suggested should take considerable responsibility for preparing their members to take part effectively, and those that are less experienced. A degree of ‘crossness’ on the part of those who were less experienced was tolerated in the way that it would not with ‘experienced’ users. Although there was a general sense that becoming better informed was helpful in terms of user involvement, a clinician thought it could be difficult if people ‘self-diagnose’ on the basis of reading online literature, and a commissioning perspective that it was unhelpful to hear primarily negative experiences of services.

The issue of ‘representation’ is an enduring one in the context of SUI. As is often the case, interviewees used two different meanings of representation, not always being explicit about the difference: they talked both about active participants as ‘representatives’ of other users, and about whether or not they were, collectively or statistically, representative of all users. One aspect of this related to diagnosis – it was suggested that it was harder to get people with a diagnosis of psychosis involved and that there were splits between people with personality disorder and other types of disorder.

Interviewees saw increasing the range of people who become actively involved as a continuing challenge. Commissioners were not good at reaching out to a wide range of people, particularly those experiencing difficulties in their own lives, which made it hard for them to get involved. There was recognition that it is impossible for one person to act as a representative for users collectively and that a single representative can become marginalised. One person highlighted a tension in the way in which experienced users can become part of a ‘groupthink model’ and find it difficult to retain the perspective of those who are not involved. Another way of expressing this referred to ‘professional users who take on the values of the organisation they are working with.’ Another issue identified was that future SUs may be very different from current users, and basing new services on the experience of those whose formative experiences were in ‘old school hospitals’. It is interesting to contrast this with the view that ‘former’ users might provide more helpful input than current users.

There was some discussion of working with user groups in order to recruit people who could act as representatives of others, but also of the difficulty of identifying people who could speak to the ‘common good’ rather than base their input on their own experience. One person talked about the value of elections as a basis on which to formally represent, but also the need to facilitate those who might be good at listening to others, but less good at speaking out with a ‘loud voice’ on their behalf. Some interviewees acknowledged that there are people who tend to ‘dominate’ in all settings – including among clinicians. Learning to work with strong and different views is part of the process of working with SUs.

The concept of ‘professional user’ is one that has attracted considerable distaste among active users. It was only referred to explicitly once in these interviews in the context of users who take on the value of the organisation with which they are working. But there were also comments that users who behave ‘professionally’ are more likely to be welcomed to take part in all kinds of decision-making and a suggestion that if users were paid to turn up to business meetings more could be expected of them. Yet ‘professional’ behaviour could also be linked to educated, middle class SUs with the skills to present views but who were considered to represent only a very narrow range of views.

User involvement discourses

From the early days of user involvement in public services in general and mental health services in particular, it has been evident that people mean and assume rather different things by this. These ideas are based in very different assumptions about the relationships between SUs, providers and public officials, the purposes to be achieved through involvement and the political significance of such shifts in ways of making decisions. The following analysis draws on a study of public participation across a range of policy areas (including health and social care)³⁴ that identified four different discourses within official policies shaping public participation initiatives: empowered public, consuming public, stakeholder public and responsible public discourses. We considered evidence for these in the way interviewees talked about user involvement in mental health and also identified other discursive constructions of what user involvement *is*.

Although the term ‘consumer’ was not used directly by interviewees, the dominant discourse within these interviews derived from notions of consumerism. The ‘publics’ (or in this case ‘users’) to be involved are those that are defined as active consumers of services, with consumer rights and interests in the crafting of more responsive services. This is reflected in the mechanisms for involvement that are described, in the values that are expressed in the way user involvement was talked about, and in the purposes it was seen to achieve (or be intended to achieve).

For some, this has come to be a ‘taken for granted’ position – user feedback is an obvious and integral part of the way they do business. Comparisons are drawn with restaurants and others who need to become closer to their customers and ensure that their products are acceptable:

... and you know it's very basic, if you come into any retail, and I'm not saying this is retail, but if you go into retail or a restaurant and you have a bad experience you're not going to want to go back are you?

Team leader

In some cases the purpose of user involvement was thus seen to be (at least in part) to enable the organisation to become increasingly competitive and be seen as a ‘modern, outward looking organisation’. This was linked with becoming a FT and becoming ‘more business like’:

One of the biggest change for the foundation trust is the sort of need to operate more along business lines ... I think, you know, to survive as a business, customers who use the service have to be satisfied with the service otherwise ... they'll feed back to commissioners that they are not happy ...

Manager

From this perspective, involving users in shaping services should mean that users are happier. Responses that evidence consumer dissatisfactions were cited and one respondent suggested that the SU movement had made people more aware of their customers. For one person developing a more consumerist approach was related both to a broadening of user involvement and to the development of regulatory procedures. Another linked this with PALS, complaints and customer relations.

Some saw self-directed support (SDS) in this context and there was mention of the need for flexible market development to enable the consumer benefits of SDS to be realised. But one person suggested this was creating ‘microcommissioners’ rather than consumers, whereas another expressed concern about the uncertain effect of a move to individual purchasing of services in terms of how feedback can get back to commissioners.

There was some feeling that questionnaires were being over-used and one person recognised the difficulty of providing negative consumer feedback while being a current in-patient.

The *empowered public* discourse is one that recognises that some social groups are marginalised and disadvantaged and that gaining a voice in decision-making about public services can be a route to challenging unequal power relations. When mental health SU groups emerged during the late 1980s this was the way they conceived of 'empowerment', and the term was also used in this way by some public service workers committed to social justice.²¹ But the term has lost much of its force in the context of official involvement initiatives shaped by consumer discourse. Only one person explicitly talked about SUI in terms of an opportunity for those whose voices are not often heard to have a say in the way money is being spent, linking this to the importance of meeting the needs of excluded groups, and recognising that such needs include matters such as housing as well as clinical treatment. This respondent located this perspective in relation to the impact of cuts and also referred to the limits of individual purchasing in comparison with more collective approaches. They also identified the discomfort that professionals can feel at giving up control over services – recognising that empowering those with little power can mean that those who were formerly all-powerful feel threatened.

For another respondent, SDS was a way of empowering individuals, whereas another linked the recovery movement to greater control by SUs and a consequent reduction in professional voice/influence. In this way of talking about empowerment, respondents were suggesting that particular models and professional ways of working could lead to empowerment and that empowerment is something staff do to SUs: 'We need to empower people to take control.' Another said users had a 'valuable contribution' to play and were 'empowered to have a unique role'. Another cited an example of outspoken users having power to access the CEO in ways not open to middle managers. Thus, the term 'empowerment' or 'power' was not necessarily related to the transformative implications of the discourse as defined above. Indeed, one person suggested the transformatory potential of user involvement could be limited by organisational dynamics and history, and another acknowledged that equating board membership with empowerment could not be justified.

The *stakeholder public* discourse identifies SUs as one among a number of groups having a stake in the quality and good governance of services. Although not as prevalent as the consumerist discourse there was evidence of this in the way some spoke about the importance of understanding how the system was viewed from different perspectives within it, in acknowledging the value of including user expertise at both strategic and operational levels in informing trust activities, and in including user perspectives in performance review processes. This perspective was linked with methods of involvement enabling collaborative ideas development following through to implementation, including making best use of resources at a time of cuts. One respondent contrasted what was seen as a positive role played by some user governors with others who were seen as having been elected to take an oppositional stance. Here board membership was contrasted with membership of a 'lobby group'. Implicit in this was the notion of different stakeholders being prepared to work together to reach decisions, in contrast with an approach in which SUs sought to pursue what was important to them.

The *responsible public* discourse emphasises the role of individuals and groups in owing duties to the state and to other citizens and adjusting their conduct accordingly. In the context of public participation and user involvement it refers to a preparedness to contribute directly or indirectly to the good governance of communities and services. There is thus some overlap with the observations about the role of 'cooperative' governors in the previous section. Apart from this it was rarely evident in these interviews. One person referred to 'responsibilities as well as rights' in relation to DNAs, whereas another referred to the jointly owned enterprise – 'what you do in order to help manage your condition'. A rather different comment evidencing this discourse was from an interviewee who talked of the responsibility of user groups in relation to their own organisation and sustainability.

One team leader identified resistance from SUs to being put in a position where they were expected to take responsibility for decisions:

Service users were . . . as an issue, bringing to the consultative meeting that we had between the consultant, myself, another team member and the service users and it was something to do with people perceiving that too much responsibility for a problem . . . the responsibility was being placed back with them. But service users said but we have come here for help . . .

This reflects what are considered to be negative consequences of this discourse: that receipt of help is contingent on being prepared to take an active role in decision-making.

Other ways of thinking and talking about user involvement were evident in these interviews. One particular feature of user involvement in mental health has always been a view of this as 'therapeutic' – a view often contrasted with involvement as empowerment. There was some evidence of this way of thinking in the context of active users being seen as role models for others; the work of the 'recovery college' in providing training, the development of self-coping strategies and the support available to people from working collectively:

You know some of the reward might be because it actually makes you feel better and is good for your well-being.

Team leader

This notion of user involvement as therapeutic has links with the responsible public discourse – if you take responsibility for your own and others' problems this will make you feel better:

So I'm a big fan of helping people to move from a more passive to a more active stance in terms of problem solving, problem management so I think involving service users in thinking outside their own specific and thinking in the broader . . . I think supports their own, you know, self-coping strategies.

Psychiatrist

The notion of *user expertise* was also evident, and there was also some discussion of user involvement as 'work' – a task to be done, something that people should be paid for. The concept of the 'expert patient' is one that has developed and been applied in many health settings since the 1990s, and there were many observations about the 'knowledge' dimensions of SUI. These reflected the value of experiential knowledge and of challenges to assumptions of 'professionals know best. However, acknowledging the significance of user involvement as an epistemological challenge to professionals is not the same as suggesting that professional power to define the issues is undermined:

. . . you know the way care is planned . . . the professional still has too big a voice often.

Commissioner

. . . when mental health policy changes it's because the psychiatrists who are seen as the most powerful group, the most qualified, the best paid, they have the strongest voice because they lobby the government and then nurses, clinical psychologists, social workers, and OTs might also have a voice and publish work but it's a united voice, it's no-one's personal point of view. It's formalised as a professional, scientific, this is the right way to go about it, this is the medication that works.

Team leader

Personal positions regarding service user involvement

We also sought to understand how interviewees saw their own position, both in terms of their personal responsibilities for enabling users to be involved and the extent to which they expressed personal commitments to this. This is important because of the likely effect of attitudes and commitments on the impact of involvement.

Some interviewees in all categories talked not only of their personal commitment, but also of responsibility for creating a culture and ethos of SUI within the organisation as a whole, or that part of it for which they had responsibilities. One spoke of her career being centred on SUI.

As the manager of a team I think you can set the tone of a team, the approach of a team and sort of the prevailing attitude.

Team leader

Personal commitments could emerge from the benefits it was seen to produce. One CEO suggested that the benefits of user involvement far outweigh the challenges. Another response suggested that commitment to user involvement at an individual level was linked to improved compliance resulting from involving users in treatment decisions. One commissioner suggested that SUI was implicated in their own credibility, whereas another evidenced their commitment by referring to recruiting a consultant to advise on developments in user involvement.

But not all of those who expressed a personal commitment considered that SUI, as currently practised, was working. Some identified specific gaps, such as the involvement of people with psychosis, whereas others spoke of the limited influence of SUs in comparison with other forces affecting decisions about service design and delivery:

I just don't think it happens. I think what happens is that decisions are taken elsewhere based on other notions or financial reasons and that is ultimately what happens I think for major decisions about things.

And some saw user involvement as 'someone else's job'. In two of the three trusts, psychiatrists indicated that they thought user involvement is a responsibility for managers rather than clinicians, and that they saw this as a lesser priority than other aspects of their work. One psychiatrist noted that in order to progress SUI, anxieties about what this might involve and their professional roles needed to be addressed. A team manager suggested that:

Sometimes a lot of staff seem to get a bit jaded on sorts of user involvement and see it as amore of a hassle, or that's extra and I still think there is a lot to be done and for people to appreciate it is the core of what we do now.

User involvement in practice

One purpose of these interviews was to identify the range of user involvement mechanisms in use within the three trusts. We did this by asking interviewees to talk about good examples of SUI – what worked from their experience? Interviewees varied in the extent to which they professed knowledge about different mechanisms and responses were often quite imprecise and uncertain. People cited examples of practices, mechanisms and methods that they thought valuable in terms of their attitudes to user involvement and its underlying purpose. For example, those adopting a consumer discourse talked positively about examples of feedback mechanisms, including technology-based surveys, indicating that they considered user involvement to be about understanding how a particular intervention is received. On the other hand, those talking in terms of empowerment, positively identified mechanisms enabling involvement at different levels within the organisation, particularly at early stages of service design/redesign.

Dialogue and working together

Some interviewees identified the value of contexts in which SUs worked *with* providers and commissioners and in which there was an opportunity for dialogue. These included mechanisms such as process mapping and stakeholder events used by commissioners:

Our plan over the next year is that we have four key events with regard to engagement and that's not just service user engagement, that's mixed, that's stakeholder and service user engagement, carers and so on. And those are your kind of . . . cornerstones so that as you develop, that is your main group and then from that group there are people who are then interested in the different work stream areas and they then work in those work stream areas as a collaborative group together.

Commissioner

However, this referred to a future plan and this commissioner reflected that the dominant mode in practice was that of consultation, rather than these more deliberative approaches. And as a commissioner acknowledged, the scope for any change of direction was limited:

. . . a key part of our work at the moment is around the decommissioning of services as a response to the savings we are required to meet. And we ensure that service users are consulted . . . I say they are 'consulted', it's 'consultation' in its more basic form to be honest. It's about information sharing. Because in terms of actually shaping the decommissioning process, I don't think they have much of a voice really in that.

In a context in which service change was often about service closure, there was some recognition that effective communication, including being honest and transparent about the limits of influence, was necessary to reduce SUs' anxiety. In relation to service redesign – particularly ward closure – respondents noted that greater involvement of service users at early stages of decision-making reduced anxiety levels and, therefore, likelihood of 'noise' (i.e. letters to members of parliament).

One context in which there is at least the potential for dialogue and collaborative working is through user governors' involvement on FT boards. However, few interviewees were familiar with this. One who was, because of being a staff governor, was positive about a 'partnership' approach to developing quality targets. Another interviewee spoke very positively about the 'respectful dialogue' that had developed in this context, although also identified what was regarded as 'outrageous' behaviour by one user governor. This person also talked of trying to develop a board with user input that would run particular services, such as a hospital. This was framed in terms of 'partnership' but was not yet in operation. But there was also a view that the introduction of formal governance mechanisms involving user governors can complicate mechanisms developed locally within the trust. There was an uncertain relationship between user governors and constituency-based members' councils looking at issues such as quality and patient safety.

Opportunities for discussion in forums run by providers to explore intervention models were considered:

We recently had a forum where we wanted people to come in and talk to us about what group work that we're doing. We had lots of ideas about groups that we could run . . . to fit the model of early intervention . . . and it was quite interesting to get the feedback . . . they actually didn't want groups as such, they wanted something else, delivered differently, educational, more workshops.

Team leader

This response is important in indicating that opportunities for discussion can enable SUs to question providers' assumptions about preferred models of service delivery. In another example, a psychiatrist spoke about being challenged about the value of medication following taking part in a debate at a research network that aimed to encourage SUs to be involved in research. But another response also suggested that the validity of the views expressed by current SUs in relation to the development of new service models could be questioned. The particular context for this was the future of day centres where current

users were seeking to maintain the services, but some respondents suggested that 'newer users' needs and wishes were in conflict with those of 'longer-term' users. It was unclear whether or how user involvement mechanisms were enabling differences between SUs to be debated and appropriate responses agreed upon.

At an individual level, there were also examples cited of dialogue between clinicians and users about medication and other treatment issues that were considered positively to reflect 'a more collaborative approach' to practice. The different levels at which these more collaborative approaches were taking place are obviously significant in determining the scope of influence that is possible.

Consumer feedback

There were frequent references to forms of 'consumer feedback' via questionnaires and postcards, as well as more interactive forums in which feedback was invited. Although there was concern in some quarters that SUs would feel constrained from criticising the services they need, for many user involvement was primarily about finding out and learning from users' experiences of services. One psychiatrist said 'Feedback on all the services we're offering should be obvious.'

The range of contexts in which feedback was considered relevant and useful was broad. This ranged from the design and layout of waiting areas: 'obvious stuff, just stupid environmental stuff', to mechanisms to collect users' views, both quantitatively and qualitatively, to assess service quality and inform commissioning decisions. Between these was the 'day-to-day' level of quality assessment that could involve both questionnaires and meetings with individuals and groups of users during visits to services.

User feedback can not only be a means of accessing views about services, but also of directly involving users: through user-focused monitoring and carrying out telephone surveys:

The users don't just go out and collect patient or service user views. They then have a place and authority to work with us on the action plan and then hold us to account for implementation . . . and our very senior directors have to go and account to user panels as to why certain things have not been done.

The importance of this link between feedback and action was reflected by a clinical manager, who had talked positively about advocacy and user groups getting feedback from SUs, and how positive feedback from users had led to the replication of the adoption of 'associate mental health practitioners' beyond the original hospital in which these were introduced. But this person also spoke of the dangers of an excessive use of questionnaires:

I think we're surveying people to death . . . I feel like sometimes we're getting poor results and we don't like the results so we survey again. What are we doing – surveying until we get the results we like? And we spend so much time surveying and we are not spending any time looking at what is behind these results and why we are not doing so well.

They went on to suggest that feedback needed to relate to specific issues where there was an active consideration of the possible need for change and where action would follow. A psychiatrist in another trust also reported an experience of being 'bombarded' by the number of questionnaires that were in use and was unconvinced about the value of these. And the following response from a team leader suggests that SUs may themselves be unconvinced about the value of feedback mechanisms:

I've observed it is a real challenge . . . despite inviting people, putting notices up and you know, in areas of erm, community erm, reception areas you know how would you like to shape this service? How would you like to give feedback? Post cards or whatever, would you like to, you know, participate in a coffee morning forum to share your experience in what you'd like to see in this team, but nobody ever turns up so it's a real disappointment.

There was one view (from a senior manager) that obtaining 'real-time' feedback on the way individual staff were treating people was important, but not something that existed to enable 'weeding out' those who were not performing well. In contrast, another perspective was that it was only after people had been discharged or had ended a period of treatment that they would be able to reflect and offer a view unconstrained by the sense that 'someone's looking over your shoulder'. This commissioner suggested that using postcards to obtain feedback on experiences of relationships with clinicians was indicative of a failure to ensure that clinicians noticed when things were not right.

Peer support

In all three trusts involving SUs in peer support was viewed positively. Mechanisms such as mentoring, support, training and a recovery college were recognised as of value both to the organisation and to SUs (both those involved in giving and receiving support). The recovery college was seen as a good example of coproduction in action and an initiative in which SUs had been involved from the start. One team leader talked of how peer support could enable a move from 'user involvement' into paid work:

We've actually been fortunate enough to get one of our workers, one of our service users onto a peer-working scheme and into a vocational position as a peer worker . . . this isn't our invention, we're just formalising things that probably should and could be happening . . . driven by the service users' agenda rather than our own . . . I think it's important to have it that way round and not think that we're great because we have achieved this.

However, there was also recognition that this way of working created challenges for teams seeking to support peer support workers within teams, and ensure that they were not isolated within a team comprising 'a group of 25 plus professionals'. A psychiatrist suggested there was a need for realism in the extent to which it was appropriate to expect services to be delivered by SUs and a note of caution about peer support being used to facilitate cuts.

Recruitment

Staff recruitment is a very specific context in which SUs are increasingly playing a part, but responses indicated some ambivalence about the way this was happening and the extent to which it impacted on decisions.

In some contexts respondents noted that user input had made a difference to the issues that were explored in interviews:

I involved service users in interviewing the GPs and what was really interesting is erm, some of the questions that they wanted to ask erm, because it really picked out whether or not the GP had an understanding of people with mental health difficulties.

Team leader

But one psychiatrist expressed disappointment that the SU panel does not get a vote in deciding who to appoint.

There were differences in terms of the point at which users were involved in the recruitment process, with a team leader in one trust suggesting users were given the option about whether to have an informal conversation with interviewees before the formal interview, or to sit on the panel. A team leader in another trust talked about involvement at an earlier stage:

Sometimes in the recruitment processes in the past we have used service users in the interview process, but we have brought them in at wrong part of the process in my view . . . they were not involved in short listing which then becomes I think . . . a touch patronising, you need to kind of encourage people from getting the job advert together . . . It is actually thinking about what questions

they might want to ask and I have seen it all the time . . . there is always a question about services user involvement the assumption that the service user only wants to ask about that, well actually they might want to ask about risk . . . they might want to ask about anything else.

This person also suggested that it is important to recognise the diverse expertise people may have beyond their experiences as SUs, and that these skills could usefully be drawn on in recruitment processes.

Collective action by service users

All the examples considered up to now involve service providers, managers or commissioners inviting SUs to take part in different ways within consultation, feedback or decision processes at different places within the mental health system. Our overall study was designed in part to answer questions about what is happening to another form of SUI– collective action among SU groups, in the context of systemic and service delivery changes. Here we consider what interviewees said about user groups and the role they were playing in user involvement in the three trusts.

Some expressed frustration about not knowing which groups to approach, and also the differing views, type of input and approach of disparate groups. Some groups were identified as having more of a ‘campaigning’ focus than others that were seen as more ‘collaborative’. From within both provider and commissioning organisations there was a strong urge to create a context in which different groups could come together to coordinate SU input, and to debate, if not resolve, any differences that there might be between them.

Thus, in one trust the attempts to bring SUs together were described as ‘fraught’, but it was felt that some headway was being made with a trust-wide involvement group. In the same area a commissioner considered that it would be beneficial if there were more opportunities for different SU groups to debate issues together in recognition of disparate views and approaches. Similarly, in another trust a manager talked of difficulties working with SU groups separately from meetings with other stakeholders. This person highlighted the benefits of individuals getting to know each other and build relationships.

One of the values of collective organisation among SUs was the important role this can play in enabling the trust to make contact with and engage a wide pool of SUs. And related to this was a confidence that the views expressed by activists were well grounded:

[The] service user network locally is fantastic, you know there are characters in there who have very strong opinions but as a group you could go to them, or I could go to them and I think their opinion would count for quite a lot . . . they’re thought through, they’re sensible . . . they engage in the process.

Team manager

Trust and commissioner benefits from collective organisation was also identified in relation to their potential to sell what might be unpopular messages:

. . . they have a relationship that we don’t have with service users and I think . . . it means that they can sell a message that . . . a slightly monolithic organisation like ourselves would struggle to do.

Commissioner

The reverse direction of communication was also identified: the value of seeking feedback from SUs on services received via user groups, as users were likely to give more meaningful responses than they might to staff/clinicians. This was also considered relevant in relation to research. The role of user groups (and voluntary organisations such as MIND) in enabling more open and honest communication and expression of views was linked to a problematic issue of trust between providers and users in some responses.

The benefits to the organisation of working with the same person who has an overview from many perspectives was acknowledged, along with a recognition that individuals who lead SU groups can be pulled in many directions and experience burnout as a result. Also relevant to this were the distinctions drawn between embryonic and established groups with or without paid workers.

In somewhat of a contrast with the benefits of collective organisation as a means of accessing a broad range of SUs, one team leader suggested that individuals within groups that are 'strong and they're independent and separate from those medical, professional perspectives' would struggle to have an opinion, whereas another thought that a minority of SUs would join a user group.

Impact

An assessment of impact is central to the aims of this study. Here we consider the types and levels of impact that interviewees thought were evident. It is important to recognise that not all interviewees expressed themselves as knowledgeable about the range of different types of involvement that were happening and also that, as one remarked: 'you can't delineate and say that thing you did on Tuesday was SUI and it's separate from the rest of your working life and that had this particular outcome . . . it's so hard isn't it to pin those things down?'

Level of influence

In part, because of their different roles and positions, interviewees focused on different levels at which it was possible to identify user involvement impact. Thus, a clinical manager noted the benefits from user involvement of improving relationships at 'all levels of the organisation', whereas a general practice commissioner mentions involving SUs in managing provider contracts. One perspective from a commissioner was that although SUs' opinions had equal weighting to clinicians in assessing tenders, it was the commissioning support department (e.g. finance) and the PCT board that had most influence over commissioning decisions.

One perspective from within senior management was that staff lower down the hierarchy could be fearful of the relationships between users and managers. A clinical manager noted 'you wouldn't as a service manager go and ask the chief executive'. But there was considerable uncertainty about the extent to which the move to FT status with the creation of user governors had any noticeable impact. Some suggested that boards of governors are effective at holding management to account, but another could identify no change.

Other responses reflecting 'high-level' or systemic impact included the overall impact of user focused monitoring owing to the fact that SUs run meetings, give results and draw up action plans for change that staff take on and report back on (e.g. improvement in crisis telephone lines). But one commissioner suggested that users were not 'comfortable thinking strategically', which constrained the capacity to impact at this level.

There were different views about the extent to which user involvement could be considered as systemic across the organisation. Potentially, user involvement in recruitment processes could impact throughout the organisation, but those who spoke about this thought it had limited impact in practice.

Changing relationships

Involving SUs in trust governance processes, service delivery, research, commissioning and treatment decision-making creates a different kind of relationship from the traditional position in which 'patients' are simply recipients of services determined by others. But in what ways did interviewees think these different relationships could be understood?

One view was that working together with SUs breaks down barriers between staff and users allowing each 'side' to get to know people as individuals and that this enabled greater trust to develop. Relatedly, and reflecting the point made above about increased treatment compliance, was that compliance was improved

as a result of the development of mutual respect and rapport. One psychiatrist described this in terms of a change in dynamic between clinicians and SUs towards partnership. Such shifts were considered to be the result not only of changes of practice within the trust, but also the way in which the internet increased information availability and initial self-diagnosis. This did not mean that they were necessarily happy about moving out of: 'this comfort zone of seeing people as a doctor/patient relationship' (psychiatrist), and thus doctors may still avoid taking part in involvement forums. There was also a view that some staff/clinicians can feel threatened by increased SUI, feeling their expertise is challenged. A rather different perspective (from a CEO) on the nature of the relationship that emerged from collaborative ways of working was that users' relationships with mental health services were moving towards coproduction.

Ways of working

Interviewees identified a number of ways in which they thought both attitudes and ways of working had shifted because of SUI. For some this was a result of becoming more aware of what living with a diagnosis of mental illness can mean, and how this helped them focus on what was important, including recognising 'the disadvantages and discrimination and stigma that service users do experience' (team leader).

Shifts in professional attitudes and organisational culture were linked to:

- a more routine approach to listening to what SUs are actually asking for
- the involvement of SUs in recruitment processes
- SUI in training for approved social workers, and in more general professional training
- challenges presented by user governors in terms of balancing risk/safety with therapeutic care in inpatient settings, and in questioning specific ideas, such as the use of the idea of 'clusters' related to Payment by Results
- a generational change with younger staff assuming that this is how they should work, (although their ambitions may be different to how the system 'actually is').

One manager suggested that there had been an evolutionary process through advocacy and user involvement in general away from a 'mental illness' model in which professionals were the only experts. A similar point was made by a psychiatrist who valued opportunities to meet with groups of SUs to reflect on the practice models being used. And a team leader stated that staff readily embrace ideas that come from SUs:

If I go into a team meeting and I'm able to say that this is something that we want to think about, we need to consider and I've got an evidence-base that includes feedback from carers or service users, that this is what they would like, people will always respond more positively and will be a lot more willing to take on pieces of extra work if it has that as part of it.

Ongoing SUI was seen as a way of assessing whether or not practice changes translated into benefits for SUs and this was also a source of sustained pressure to change because there are still 'numbers of staff who just don't get it . . .' (team manager).

Service delivery

Interviewees identified a number of specific service changes resulting from SUI and some suggested that small changes to practice could have a big impact. Thus, the following list suggests changes of different orders of magnitude:

- the introduction of bags for medication collection
- increased demand for psychological therapies as result of increased SU awareness and pressure
- developments in home care and treatment outside of hospital

- developments in crisis and out-of-hours services, including a crisis house, crisis cards and access to a crisis telephone service
- support for associate practitioners in hospitals
- maintenance of a day centre.

Other service changes related to the impact of SUI on the specific assessment tool being used which impacted on the way in which service providers viewed users, and the development of user-defined quality measures. The impact of personalisation was yet to be felt in any substantial way and there were differences of opinion about the likely benefits, but there was a suggestion that this would highlight the rather limited approach often taken by professionals.

Effects on service users

Service user involvement can impact on SUs as a result of service and attitudinal changes it produces, but also directly through the recognition that users get for the knowledge and expertise they bring to decision-making. Interviewees' comments related primarily to the second of these sources of impact, although the introduction of the recovery college, itself seen to result from SU influence, was considered to have had positive impacts.

One commissioner noted 'enormous personal benefits' to users of being involved in conducting research. This person noted that user focused monitoring is being used, but believes more involvement in conducting formal research for SUs is desirable. A psychiatrist noted marked self development in a particularly active SU who 'pushed the agenda forward' over a period of years, and another psychiatrist noted the positive impact on a SU's recovery from joining involvement processes. There were many comments about involvement activity leading to paid employment.

But some interviewees also identified negative impacts of involvement. There was a reference to stresses associated with user involvement: of someone being 'pulled in every which way'; specific stresses associated with the content of documents that needed to be read, and concern that expectations of influence may be raised when in fact, in their opinion, there is only one course of action. In one case such concerns resulted in thinking about how to have discussions with users at the start of involvement activity about how stresses could be managed, with both staff and the SU taking responsibility should the person become unwell.

Barriers to impact

Clear threads of concern emerge around the potential threat that increased SUI poses to professionals. One such relates to the notion of risk and professionals' perception of their responsibility for managing this within a culture that is risk-averse. A chief executive spoke of prioritising evidenced based practice and adherence to National Institute for Health and Care Excellence (NICE) guidelines within the context of balancing risk, safety and therapy. However, a Commissioner noted that they are observing change in relation to this with the implementation of personalisation and puts this down to the involvement of third parties who were referred to as 'bridge builders' who could challenge professionals' perceptions of risk.

A second thread relates to professionals' concerns that their expertise is challenged and/or devalued as SUs become increasingly involved in service design and delivery. Peer support was one focus for these reflections, and another was a committee related to drugs and therapy. It was in the latter context that there was an emphasis on technical training before professionals would be comfortable for SUs to play a part in decision-making. This was contrasted with user input to the physical design of services which was not considered to require specialist knowledge.

Evidence of some continued sense of 'threat' to professionals was in contrast to the view of a commissioner that times have changed: 'I think many years ago providers couldn't understand even why you were talking to people that were using services and felt affronted by the fact that people were trying to change services'. A manager with an occupational health background identified the continuing dominance of the medical model within mental health services, suggesting that some staff who work to a 'diagnosis and cure' model

do not recognise users as experts. And another manager described a situation where someone who both worked in and used mental health services was introduced to staff in terms of their 'professional' identity, but when their identity as a SU was disclosed:

The perception changed really tangibly . . . well you're an expert because you are from the Centre of Mental Health and you are a service user as well . . . so what we found in those reviews is the idea of recovery, the idea of working alongside service users, people talk the talk but when you start to chip away at what their ideology is it is very much around someone who couldn't work or someone who can't engage in something because they are too ill.

Institutional rules and norms

When SUs interact with providers, clinicians and commissioners they are entering into territory that is shaped by professionalised and official procedures, assumptions and ways of doing business. Here we explore how institutional rules and the norms, that shape expectations about appropriate behaviour, impact on the extent to which SUs can influence services, policies and procedures.

A clear message emerges from interviews that attitudes and practice related to SUI are heavily influenced by the prevailing culture within trusts and the wider context of the NHS and local government. Interviewees were very conscious of pressures associated with current changes, including the tight deadlines required in relation to recommissioning and reconfiguration of services, meaning involving users is 'relatively tokenistic' and unlikely to have real impact on 'what we cut and what we retain and what we change' (commissioner). Staff unhappiness with changes taking place were associated not only with low morale, but also poor communication with SUs in the view of one psychiatrist. In a context in which commissioners and providers are working out what their relationship can and should be, there was a recognition that involving SUs in managing of contracts 'fundamentally shifts' the power balance between users and providers and that this is very challenging to providers' existing culture.

These negotiations about systemic and service changes were seen to create specific challenges on top of what can be considered enduring issues that need to be negotiated in relation to SUI. Those identified were:

1. Managing other responsibilities, such as risk and safety, alongside commitments to user involvement. One context for this was the implementation of the recovery model:

We need to empower people to take control and have choice over what they do in their life, then that's what we should do but as soon as there's a serious incident, you can't all of a sudden . . . make a hundred recommendations on kind of risk management . . .

2. Staff anxieties about having SUs at business meetings in terms of concerns about what can and cannot be discussed.
3. The importance of being open about what can and cannot be influenced. A view that there was a need for 'honesty' about statutory obligations was related to learning from past experience of not doing this, raising SUs' expectations and causing frustration.

Some recognised the way in which norms about behaviours and 'ways of doing things' can make it hard for SUs to play a full part. Others appeared to assume that the ways formal organisations usually operate is the norm that users need to adapt to:

The sort of behaviour of an NHS meeting is that some of us know how to behave in a meeting. I don't think we have been very good at setting up what we want service users to do.

Manager

Others also spoke about meeting conduct. For example, one psychiatrist noted a need for a strong chairperson at meetings involving SUs, but then reflected that this is true in many meetings, while another manager suggested that formal meetings are not the way to achieve effective involvement. A commissioner recognised the conflicting cultures of the NHS and ULOs and that power differences means it is the NHS ways of doing things that dominates in relation to how meetings are run, and what information is made public. This person spoke of the 'deadening bureaucratic infrastructure of the NHS and the [local authority]' that made user involvement a poor experience.

It was suggested that there was a need for a variety of ways of ensuring different SUs can be involved, and that those with psychosis are harder to involve in traditional ways. However, this manager spoke of adjusting meetings rather than exploring alternative types of forums. For example, they recognised the need to be mindful of the fluctuating health of users, the possibility of 'tweaking' the system to enable continued attendance, and the need for training in technical issues (e.g. drugs and therapeutics) in order for SUs to contribute alongside paid workers in committees. In contrast, another manager talked of observing SUs becoming part of the system 'groupthink' and, thus, losing the capacity to 'hold organisations to account'. Only one respondent talked in terms of the potential for SU groups to campaign more in relation to policy initiatives.

Interviewees identified some specific processes that can undermine effective SUI. One related to the emergent processes of commissioning: the finance department (or commissioning support unit) have scoring systems to assess tenders which are not understood either by clinicians or SUs, but carry equal (if not more) weight than the views of each group in terms of reaching decisions. The other is an enduring challenge in relation to the recompense of SUs for their input: systems set up to facilitate payment to SUs can cause stress due to the inflexibility of bureaucratic systems unable to pay people over long period of time to reduce weekly payments in line with benefit regulations.

Ways in which constraints resulting from institutional ways of operating might be reduced were identified. These included the suggestion (from a psychiatrist) that leadership from senior clinicians can ensure broad support; and that ensuring information is given in suitable ways will aid users to understand what the trust was doing and how it fitted the national context.

There was a view that current unsettling of relationships due to systemic changes provided opportunities for user influence. Thus, a senior manager suggested that there can be differences between what SUs say they want and what commissioners want to buy, but there is also the potential for SUs to put pressure on commissioners. They also suggested that health and well-being boards offer opportunities for political influence. However, suspicion that central control from the national commissioning board will soon be introduced caused interviewees to consider that opportunities for influence will be limited. There was a difference in view about whether the points at which user influence can be exerted will be limited due to diversity of providers, or whether a provider monopoly was antithetical to user influence. But one CEO thought it is not possible to simply transfer current systems of user involvement into a market-driven context. And a more 'generic' landscape of involvement: via public and patient involvement forums, LINKs and Healthwatch was not necessarily helpful to the mental health context.

The requirement to make significant cuts was considered to impact the level of openness and honesty professionals felt able to adopt. A manager suggested their instinct is to protect users, but involvement from early stage is necessary to work in partnership in this context. A psychiatrist recognised the pressure on managers to effect cuts quickly, but suggested that it 'wasn't just service users who weren't consulted well, neither were primary care groups consulted well'.

Both team leaders in one trust talked about the challenge of ensuring SUI is 'afforded a significant position' when budgets are collapsing:

... we know we're driven by finances, so if I go to my managers and say it's really important that we develop a better service user ethos they will say 'well fine but you haven't delivered on your outcomes and your service is under threat and you'll get reviewed and you won't be there any more'.

Staff nervousness of losing employment was identified in another trust, whereas in the third trust the use of peer support workers to reduce costs was being openly discussed. Performance management was also a focus for unease. One commissioner noted a resistance to SUI in this because of the subjective nature of user experience. A manager elsewhere thought the ideal would be that SUs were involved in finding efficiencies, in assessing key performance indicators and providing live patient feedback, but this is not happening at present.

Service user involvement itself is a focus for performance management and the following response from a team leader suggested that the way SUs perform within involvement initiatives was itself a focus for assessment:

... one of the challenges we've got with services is that we're all under, you know, lots of pressure to deliver on targets ... the NHS has to deliver value for money and deh-deh-deh ... and I think if the representation from ... whichever group it is or whichever individual, it is not at a level where that individual can really participate, of course it's going to be difficult ... You know, so I think selecting people appropriately ... I suppose just by virtue of being a service user doesn't necessarily qualify someone to participate in the same way we all have to be selected appropriate to, you know, it's no use for the individual who's been selected thrown in at the deep end and of course they don't deliver.

In addition to identifying changes taking place across the board in mental health services, interviewees also discussed the significance of local contexts. Trust A was involved in a consultation on a merger and there was a view that if this happened it would make SUI more difficult. Changes in both geographical organisation and a bringing together of assessment and treatment services in trust C were also considered to have negatively impacted user involvement. A shift away from local decision-making was also identified as problematic in this context. And there was also a view that an opportunity had been lost to consult clinicians and SUs together in a recent process of service redesign. This was an example of consultation after initial ideas had been developed, rather than in the initial workshops and was considered to indicate that the trust was 'frightened' of earlier involvement.

Conclusion

We draw on these interviews further in the sections that follow. They were a rich source of insights into how senior staff are thinking about and responding to SUI. They demonstrate that there has been a substantial shift in organisational culture over the last 25 years with respect to assumptions about the place of SUI. They indicate a primarily positive view about the beneficial impacts of this, and a commitment to address the enduring challenges and acknowledged negative impacts rather than see these as reasons for not involving SUs.

User-led organisations

Introduction

The main task for our ethnography working with six ULOs was to see how they interacted with managers in pursuit of the goal they had set themselves. Previous work, starting with looking at the implications of the *National Health Service and Community Care Act 1990*^{22,23} but continuing well beyond this,⁶⁰ has surveyed the views of managers and of SUs involved in organisational change. There is a duty on purchasers and providers to consult with users of public services but a large literature suggesting that this usually takes the

form of rubber-stamping decisions already made by managers.^{38,61} This literature also almost uniformly finds a discrepancy between what managers are prepared to do to facilitate SUI and the aspirations of mental health SUs themselves.^{36,62} It is reported that managers continue to set the agenda in quite a restricted manner, both literally and tacitly, whereas SUs have a more wide-ranging set of desires including an end to social exclusion and the exercise of citizenship rights.^{21,63,64} This links back to the argument in *Chapter 1* about SUI constituting a new social movement. In this respect, Barnes and Shardlow⁶⁵ have argued that in modern public services, individuals are positioned as *both* consumer and citizen, in that they have some power to choose even in a quasi-market but that they also have a role in holding services to account. However, this is problematic for users of mental health services because they often have limited power of 'exit' and so must rely on voice. The exercise of citizenship rights is also difficult as assertiveness and emotion do not fit with institutional norms of appropriate behaviour (but see below) and may be 'pathologised' as a manifestation or return of symptoms.

As we said in *Chapter 1*, and will elaborate in *Chapter 4*, this study took place in turbulent times. The *Health and Social Care Act 2012*¹⁰ received royal assent as we conducted our work, opening up the provider market to a much greater extent than was previously the case. NHS Choices will be extended to those with mental health problems, and already service reconfigurations have led to cuts in statutory provision in some regions and a growth in third-sector facilities, including those led by user groups.⁶⁶ Perhaps paradoxically, the 'recovery movement' has played a role here, with slogans such as 'get a life not a service'. This might presage a strengthening of the 'customer' role, although two things mitigate against this. One is the slow roll-out of personal budgets in mental health and their ideology of 'individualism', which we will comment upon later. The other is that the choice of just walking away from services remains closed to those using them under some form of compulsion or by subtle pressures implying that exiting services constitutes a grave risk. There is then a modern form of the old tension between giving public sector customers choice and seeing mental health service users as risky.⁶⁷ Financial pressures may lead to withdrawal of services from many, but the focus on risk intensifies the 'revolving door' situation. At the same time, people not deemed risky may be denied a service and remain isolated 'in the community' as personalisation has not materialised or the criteria are inappropriate to mental health SUs or constitute a very high threshold.

It is worth taking a step back in history to consider how, in the 1980s when national organisations were forming, and then in the 1990s with a blossoming of local groups, managers and clinicians were viewed and approached. In particular, it is worth considering some tensions. The first concerns autonomy, which, as late as 10 years ago, Rose *et al.*³¹ argued was essential to successful user involvement in change management in mental health services. In the early days of the SU movement, the tension revolved around autonomy and collaboration, both in terms of group membership, as such, and in relation to decision-makers. Unlike the present, when nearly all ULOs are made up solely of SUs and ex-SUs, even radical organisations such as Survivors Speak Out, as well as many local groups, had a membership category of 'ally'. These were most often carers, those working in the voluntary sector and sometimes social workers or academics. The presence of the third sector and social workers was partly due to the activities of some groups around the closures of the old asylums, but also because many thought survivors on their own did not have the power to bring about the changes they sought. At the same time, key decision-makers were regarded with suspicion and even those who promised to be allies could find themselves sidelined. Consultation was not trusted as it was felt that users were being deployed to rubber-stamp decisions already taken. One aspect of the prevalent attitude towards decision-makers was that many organisations preferred to conduct negotiations 'on our territory'. They wanted managers and providers to come to them rather than the reverse, even when they had little in the way of places to meet. As we saw earlier, some managers used a strategy of declaring themselves on the side of user groups, at least while it suited them.^{36,62} The issue of autonomy was still key to some of our groups as we shall see but it was not unproblematic.

The issue of autonomy is complex, however, if we look at the management literature. Iles and Sutherland³⁷ argue that the role of the 'customer' in organisational change is usually that of an external stakeholder. They have some control and power over the end product but are not usually embedded in the

organisations that produce this end product. Public services though are not a commodity and they are not even parallel to the service industry, although some argue that they should be. The reason for this is that many recipients of public services are there in a long-term relation and, therefore, have a stake in the internal workings of the industry. In this respect, some mental health SUs are perhaps a limit case because they live their lives as *internal* stakeholders. The control wrought over the lives of SUs in the days of the old asylums could be argued to have been replaced by mini institutions in the community.⁶⁸ At the very least, the concern over continuity of care suggests a dispersed service system still catering for many aspects of the lives of those SUs deemed to have 'severe and enduring mental illnesses'. Reconfiguring services may mean that some of this will be withdrawn or changed but it is probably still the case that mental health SUs are more embedded in the services they receive than any regular 'customer' even of other public services. Beyond this, changes in the relationships between those who provide and those who use mental health services over the last 25 years have created a number of different identities beyond that of 'SU': 'experts by experience'; peer supporters, user governors, for example.⁶⁹ Barnes argues that the mental health SU movement has had to change to encompass these identities 'offered' from within the mental health service system and this further complicates the 'inside'/'outside' debate.

What does this mean for the autonomy of ULOs? It does not dispute the argument that SUs need their own space to decide what to bring to the table in consultations with decision-makers. However, the issues that concern them are likely to be those that pertain to the internal workings of organisations, such as provider trusts or social services facilities. From the start, SUs in mental health have claimed the right of a place on decision-making bodies that govern the policy and strategy, as well as the day-to-day workings, of organisations.²¹ Whether or not this has been effective is a moot point, but it is now accepted policy and has been for some time. Further, some SU groups have set up their own – 'alternative' – user-led services and these clearly require that the groups running them are autonomous in some sense (Faulkner A, SU consultant researcher, 2013, personal communication). Funding constraints may compromise this and make such initiatives precarious. There will also be contractual obligations from funders. Autonomy for ULOs then is complex.

A further issue already alluded to is appropriate behaviour for user involvement activities, who defines this and the capacity of SUs in mental health to measure up to expectations of providers and other 'officials'. There is another tension between managers and providers wishing to hear the 'authentic voice' of experience and the requirement of what Simpson and House⁷⁰ call 'coherence'.³³ In the early 1980s, a very embryonic user movement produced a Channel 4 documentary called 'We're not mad, we're angry'. Today it appears mild and somewhat stilted but clearly was meant to pre-empt the view that expressions of anger with mental health services can be reduced to pathology. The response of SUs and their organisations to this balance between discourses has been varied. Some tried to learn the language of management and consultation, whereas others prized their own discourse, linking back to what was said above about autonomy. Interestingly, in our deliberative workshop with senior staff, one chief executive took issue with this argument, saying that 'management speak is meaningless'. Others present said that a SU presence in staff training was valued precisely because users spoke their own language, bringing home to staff the reality of living with a mental health condition. The workshop concluded that different ways of speaking about users' experiences were needed in different organisational contexts. Our ULOs were certainly diverse in how far they were prepared to adopt a corporate language and there were also differences within the groups themselves.

Nearly all of the literature that examines the relation between managers and other decision-makers and ULOs studies the two groups separately. In this chapter, we report on an ethnography with six ULOs, which included observations of their meetings with managers and their own reflections on these in the form of diaries. In this way, we hoped to capture more of the dynamic of the interactions and so identify *in vivo* what facilitated progress, defined by both parties, and what impeded it or what the 'sticking points' were. Although earlier work could counter pose the views of decision-makers and those of SUs gathered separately, here we bring them together in order to shed light on some of the issues raised in this chapter as well as elsewhere in the report.

The user-led organisations

We aimed to recruit one 'traditional' and one 'specific' group per trust in order to utilise Yin's⁵¹ conceptual framework of literal and theoretical replication in case study methods. In the event, in trust A we were approached by a third group who were keen to be part of the study. In trust B, we failed to recruit a specific group despite much effort. Both a traditional and specific group were recruited in trust C. To preserve anonymity, the groups have been named as follows:

- trust A: traditional group-metro group
- trust A: specific group-arts group
- trust A: specific group-identity group
- trust B: traditional group-evaluation group
- trust C: traditional group-county group
- trust C: specific group-research group.

We have ordered the accounts of the ULOs conceptually in order to bring out the themes discussed above.

Trust A: traditional group – metro

Closure

One of the selected ULOs was forced to close its doors near the end of the research period. This was one of the 'traditional' groups. Indeed, it was a branch of a host organisation that had enjoyed quite a reputation in the national user movement and had much success in campaigning in the past. When we began our research the host organisation – which, in turn, had been part of a national non-governmental organisation (NGO) – was experiencing extreme managerial, financial and legal difficulties. The legal difficulties had led to disaffiliation from the national NGO, with consequent withdrawal of the main funding source – the proceeds from a charity shop. An interim manager was brought in from outside the mental health sector and he negotiated a merger between the host organisation and another branch of the national NGO, which effectively meant the closure of the ULO observed.

The goal metro set itself was to improve communication between itself and purchasers and providers. The group met monthly, with group members only attending the first half of the meeting, and purchasers and providers attending the second half. We also observed three meetings between group representatives and decision-makers and collected the reflections of a diary keeper. In the three meetings between representatives of metro and decision-makers it became clear that the latter found the group meetings difficult and that communication was not viewed as good. Adjectives such as 'challenging' and 'confrontational' were used, and in terms of the goal it was clear that communication started from a low base. Difficulties were experienced by group members too, who complained about 'jargon' and difficulty with documents being met with referral to other documents. Although there was agreement that members of the ULO were the harbingers of 'rich experience' this tended to be outweighed by the problems of communication expressed by both sides.

These reflections pertain to what was said above about hierarchies of language. Metro did not wish to adopt corporate language and this was one way in which it prized its autonomy. This could be evident within meetings with decision-makers when the decision-makers asked for more 'formal' information, for example monitoring data, and representatives of the ULO responded 'but we know from experience'. In fact, there were differences with respect to this within the group. The member who spearheaded the goal of improving communication did adopt more measured tones in the meetings with decision-makers, which we observed. But in the group meetings many members were forthright, outspoken, angry and worried, and this was not always regarded favourably by the interim manager, still less the decision-makers who attended the second half of the meetings.

Language is one way in which appropriate or inappropriate behaviour and conformity to institutional rules and norms can be expressed. Other aspects of this ULO's willingness or unwillingness to play the management game were also evident; they could even be expressed at the researcher, as when one member said dismissively that one of the researchers was 'from a middle-class family'. Others felt the need to leave the room when things got particularly heated.

At an organisational level, it was repeatedly said that metro should form alliances with other groups, including the 'in-house' trust user group and the local LINK. It was also suggested that the local user experience survey was more informative than the 'anecdotal' experiences and complaints brought by the ULO members from the services they represented. This opinion was also voiced by two of the senior staff interviewed and perhaps reflects the importance now attached to patient experience surveys at a government level. It was further suggested that the experiences and complaints brought to the meetings should be made 'official', perhaps by putting them on the appropriate forms. Metro resisted all of these suggestions, believing that the members represented the grassroots experience of SUs and that they 'really knew' what was going on on the ground. Even the member who was spearheading the goal of improved communication was concerned at the idea that they should link up with other ULOs and similar organisations, again on the grounds that it would compromise autonomy: 'I worry we will be marginalised'.

There was an interesting element to an awayday held by the group. At one point, discussion turned to the group's history. There were expressions of great pride in what the ULO had achieved in the past or in campaigns, which, although ultimately not successful, had been a source of solidarity. But the group appeared to realise that these days were past or, at least, they would have to reconfigure any new campaigning endeavour. Ultimately, during the period of our ethnography, although some headway was made in improving communication between some members of the ULO and decision-makers, it was not enough to stop the merger of the host organisation, its disaffiliation from the national NGO and the consequent loss of metro itself.

Trust A: specific group – arts

Struggling and strategising

One of the specific ULOs was an arts- and creativity-based organisation, which was effectively a user-led service providing workshops and other activities to mental health SUs in two of the boroughs in trust A. At the time of the ethnography it had just lost core funding of 30% from the trust and the organisational goal was to gain funding to run a training course and fund a co-ordinator to help SUs prepare plans for personal budgets. In fact, during the ethnography, the CEO was observed constantly trying to obtain funds for different activities but the personalisation agenda is key because it is government policy and apparently supported by the local authority (but see *Personalisation*, below).

The CEO emerged in our ethnography as the vital figure in the organisation. She was very experienced in user involvement activities and had been CEO for many years. She was content to adopt corporate language and to comply with other institutional rules and norms in her conversations with decision-makers. She was observed to constantly highlight possible opportunities for the arts group when conducting specific negotiations and even to make use of the presence of the ethnographer in meetings in a strategic fashion. There was none of the difficulty with language and behaviour described in the first case study, and, indeed, in interview she appeared to genuinely like the managers with whom she interacted, describing them as 'quite straightforward'. She appreciated that forging good relations with decision-makers was important for the organisation's future success. Observations showed that managers were sympathetic to the CEO's concerns regarding how cuts were affecting mental health SUs and there was an element of mutual frustration. An example concerned the closure of most of the day services in one of the boroughs together with a lack of replacement with personal budgets. Some SUs were using the premises of the ULO, designed for arts and creative projects, as a generic drop-in to replace the lost provision. It was agreed this was highly inappropriate and potentially problematic in health and safety terms.

The CEO played a strategic card in another way. In talking to the ethnographer she was at pains to show how, as a ULO, her group had intimate knowledge of SUs' needs, aspirations and capacities, which stemmed precisely from them being run by SUs. However, in her interactions with managers she did not refer to her organisation as user led. She adopted a professional stance, positioning herself as an on-the-ground worker who had similar experience to any front-line worker in the trust. She used the stories of people who used her services to make her points but was not observed to use her own story. In this way, she finessed the very division between managers and SUs that was emphasised in the first case study.

However, the CEO was very aware of how the current financial climate could affect her organisation's autonomy, which, in interview with the ethnographer, became clear was something she prized. She saw her organisation as a user-led service provider, able to meet the needs and wishes of mental health SUs precisely because it is led by people who have experienced services themselves. In her view, this autonomy was compromised by the financial climate and the relations she had with funding organisations. Requirements for constant bidding for funding, monitoring and reporting meant that the organisation risked being funding driven rather than goal driven. This she saw as not particular to her organisation but a more general risk for ULOs in the current financial and policy climate.

In terms of the goal to fund a programme for personal support planners, the ULO succeeded in securing only one-third of what it had bid for. At the same time, during the ethnography, demand was outstripping supply but not in the way expected. Many SUs wanted to use the programme to write their *own* personal support plans. Historically, this would have been a good example of having ULOs involved in personalisation but the status of this policy now appears ambiguous.

As stated, the ULO was constantly involved in trying to find funding for particular projects. Even as the specific goal set for the ethnography was not reached in the time of the research, other attempts paid off and funds for other services were secured. Although this ensured the sustainability of the organisation, it also speaks to the worry that the services it can deliver are those that appeal to commissioners rather than those set by the ULO and its SUs themselves.

Trust C: traditional group – county

Working with complex structures

The third ULO to be considered is a traditional one with a long history of involvement in a rural setting. Unlike the arts organisation discussed above, it is not primarily a service provider but acts to ensure SU in the planning and delivery of mental health SUs in one of the counties in the trust and is also involved in training and research. Like the previous example, however, the CEO of this organisation emerged as a key figure during the ethnography. She has been active in the group since its inception in 1997.

The local trust was engaged in a reconfiguration of services at the time of our research and the goal set by the ULO was to make this reconfiguration as 'user friendly' as it could be. The ULO decided the best vehicle for this would be a committee comprised of commissioners, SUs, carers, GPs and advocacy organisations. This committee was chaired by the CEO of the ULO with some administrative support from commissioners. The committee's primary function was to enable users of mental health services to engage with commissioners and commissioning decisions at a strategic level. The reason this committee was selected as a vehicle for pursuing the goal was based on a belief that this would be a powerful body, offering potential for SUs to have influence. However, from the start, one commissioner queried the appropriateness of the forum as a site to ensure user involvement (as well as the presence of the ethnographer) on the grounds that the service reconfiguration would have to be implemented by the trust and so the ULO should be dealing with them. However, the trust did not involve the ULO in its deliberations regarding the service reconfiguration, preferring to relate to the local PALS. The tension between autonomous user groups and 'in-house' involvement is found here as it was with our first case study. The ULO was successful in getting a senior trust manager to attend the commissioning committee, although subsequent invitations to trust staff were not answered. The trust manager then invited the ULO

chairperson to meet with him, which resulted in the ULO achieving representation on the trust body concerned with the implementation of the new service.

Once again, the CEO of this ULO positioned herself as having special intelligence in the sense of knowing what was happening on the ground. She was also aware of more general feelings on the part of SUs that communication with the trust could be improved in respect to the service reconfiguration. She rejected the argument that a particular forum should not be attended because it was mainly of interest to staff and to do with the internal workings of the trust. This links to what was said above concerning mental health services user groups having more of an 'internal' rather than 'external' stakeholder status, although trust representatives tried to position them as the latter.

The structures within which the ULO and its CEO had to operate were very complex and the original forum itself became more complex in structure, developing work streams to try to avoid the focus of their goal being put in a tokenistic position. In addition, it was observed that agendas and minutes of the trust-led forum came out very late, sometimes points raised by SU representatives were not minuted and detailed feedback was often not forthcoming. The CEO, as chairperson of the original forum, also seemed to experience 'role strain' in her capacity as both chairperson and SU representative.

In the context of this complex structure, it is noteworthy that the CEO made use of longstanding relationships she had formed in the past. In particular, she is used to working with the senior manager in the trust responsible for the service reconfiguration, and made use of that relationship at a one-to-one level to progress her goals. On the other hand, there were clear tensions in the relationships between the ULO and PALS, especially around channels of communication between trust management and SUs over the new service configuration.

The members of this ULO were working in a context of organisational complexity and change. It is perhaps not surprising that the CEO expressed frustration at the amount of work involved in the pursuit of her goal and of course this was not all she was involved with. She described herself as 'tired and worn' and we saw above (see *Managers', commissioners' and clinicians' views on user involvement*) that providers and commissioners perhaps do not appreciate the toll involvement work can take, especially when groups and individuals are trying to navigate complex structures in a way that both complies with institutional rules and norms and retains a SU voice.

Trust B: traditional group – evaluation

Adapting by focusing a user-led organisation

The fourth case study is also of a traditional user involvement group, this time in a metropolitan context. It emerged in the 1990s and the current director has been in post for > 10 years. In that time it has refocused as an organisation, concentrating on evaluation, research and training. During the ethnography, the group undertook an audit of the trust's rehabilitation services, including the views of both SUs and providers. The director and other members worked closely with trust staff throughout the project. The end of the audit was marked by a planning day and the work will be taken forward in the evaluation group's training programme.

It could be argued that this ULO has captured a niche market. Patient experience surveys are now commonplace in trusts and there is much talk of metrics and dashboards. However, these surveys are rarely undertaken by SUs and still less ULOs. Moving into research has allowed the ULO and its director to claim to bring the SU experience to the attention of managers in a novel fashion. At the same time, research is held in higher esteem than the kind of 'anecdote' that constituted a problem for our first case study. Research can claim to be 'representative' and the ULO's capacity to follow up with staff training means the research does not gather dust on a shelf but is actioned. Similarly, the director told the researcher in interview that she did not feel 'threatened' by the development of user governors because their connection to user groups was generally tenuous and unsystematic.

Nonetheless, the ethnography revealed some difficulties. These again revolved around complexity and changing structures. In interview, the director drew a distinction between senior managers on the one hand, and middle and operational managers on the other. The former were enthusiastic about the work of the ULO, whereas the latter were more resistant. She described having to engage the help of senior managers to overcome blocks at more junior levels while at the same time she felt the ULO had ultimate responsibility for keeping the project on track. She wondered whether or not the level of organisational change meant that some middle and operational managers were themselves frustrated and tended to see SUI as 'somebody else's job'. There was a particular issue around clinical staff whose medical training may not equip them to involve SUs in their care at an individual level. In this case, the 'go-to people' whom we describe in the *Discussion* are senior staff.

Trust A: specific group – identity

Attaining a goal: at a cost

This ULO was a specific one and it represented a minority group that traditionally has been badly served by mental health services. It was a small group, again with a strong leader with many years' experience in the user movement. This experience had given her impressive leadership qualities but also meant she was mindful of the need to be democratic and draw other members of the group into all discussions and decisions. Our observations showed that this was not always easy.

The goal set by the ULO was to secure funding for a development worker. A funding bid was prepared for the local trust's charitable arm. Quite near the start of our observations, there were meetings between representatives of the ULO and the social inclusion officer of the trust. As it became clear that some aspects of the bid were too difficult for a small group to handle, an alliance was formed with a large NGO representing the minority population and at the close of the ethnography funding had been secured and the development worker was in post. However, the process was not a smooth one.

The leader of the ULO was clear from the start that the group needed to retain its autonomy. In particular, she did not want the development worker to be based in the trust or have any line management accountability to the trust. This we have seen with other groups. She was of the opinion that the in-house user involvement in the trust was dominated by 'white upper class' people who would not understand the specific issues facing this group. Other group members agreed with this. However, there was a question of where the development worker, as a paid employee who needed to be on a payroll at the very least, could indeed be based.

This issue, together with the complexity of the bidding form, particularly its financial aspects, led the group to approach a large NGO. This group agreed to help and to host the development worker if the bid was successful. The trust charity eventually did approve the funding and the ethnography then moved to observing the recruitment process. There was a flurry of acrimonious e-mails, which the ethnographers were copied into, between representatives of the ULO and the director of the NGO on the subject of the job description and who would manage the worker. The ULO members were worried that the worker would be 'taken over' by an organisation that knew nothing about mental health. They referred again to their specialised knowledge as did other groups we observed, but this time in relation to a third sector organisation. An example was the group's desire to have a worker independent of mental health services, whereas the NGO believed a mental health professional would have more authority. These tensions were evident throughout the observations.

In terms of negotiating style, the leader of the ULO and another prominent member tended to use very lively language in their e-mails, whereas the director of the NGO was more measured. However, ultimately a compromise was reached and the leader of the ULO accepted that having the NGO on board meant they now had more 'clout'.

In her reflective diary and in interview, the leader of the ULO expressed the impact of the responsibility she shouldered on her own health and well-being. Although she sustained a strong and active leadership role, at the same time her personal well-being suffered. Once the development worker was in post, she was relieved of some of this responsibility and so, although the process we observed involved significant personal cost for her, ultimately she benefited at an individual as well as a collective level.

Trust C: specific group – research

Inside out/outside in

The final group was also focused on research but more intimately tied to the trust. The group was established to advise on the trust's research governance on SUI, provide advice on the involvement strategy for research projects, and fulfil the role of a critical friend, combining different kinds of expertise to contribute to the methodological refinement, quality and impact of research. The person who was employed by the trust with a remit of developing SUI in research established the ULO and, at the time of the research, was its chairperson. It was not necessary for the same person to occupy both roles and as the ethnography drew to a close new posts were being established and discussions were under way to address difficulties that had arisen related to this dual role.

It became apparent that interpersonal relationships were critical to the success of embedding user involvement in this part of the trust's governance structure. Both diary keepers (one was the chairperson of the ULO) had a longstanding and positive relationship with the director of research. He helped to navigate many of the issues that arose with other trust staff and was generally facilitative. It was observed, however, that sometimes the chairperson of the ULO had held conversations with him of which the other diary keeper was unaware, and this might have compromised her ability to pursue goals on her own. On the other hand, the second diary keeper felt able to speak more assertively on occasion, as she was not an employee of the trust.

Being an employee of the trust meant that the ULO chairperson was very familiar with organisational rules and practices, and with the general culture of the trust. She was observed to be confident in negotiating with senior staff and to know her way around the procedures of the department. She made full use of her good relationship with the director. However, she wished the ULO to retain a degree of autonomy and appreciated that her dual role made this difficult. She was much more embedded in the trust structures than the other ULO focusing on evaluation and thus had access to management at all levels as well as clinical academics. On the other hand, the ULO lacked the freedom of the other group and this became apparent when the issue of setting the research agenda was raised.

The second diary keeper echoed many of our other groups in stating that she would not become involved in any other user involvement activity in the trust because it was 'tokenistic'. She believed the chairperson of the ULO did it 'properly'.

At the end of the ethnography the conclusion was that the ULO had established more influence over research governance for 'in-house' studies, but less so for hosted studies. Just as the arts group found themselves hidebound by commissioning priorities, audits and monitoring, so this group had to work with competing priorities within the research department, such as the necessity of bringing in money (securing grant funding), the necessities of hitting recruitment targets and requirements for publication so that the trust would be recompensed for its research efforts.

The final issue that exercised the chairperson of the ULO was less her employment in that particular role and more her dealings with the human resources department. Rules and regulations for employing staff meant that lived experience of using mental health services did not count as a qualification for more senior posts and so, in recruiting others to involvement posts, there were limits on what could be offered. Although there were some difficulties with holding a dual position in relation to research, the difficulties loomed much larger in relation to the wider organisation.

Conclusion

In the changing and dynamic climate in which our research took place, groups were forced to adapt. The one group which found this nigh impossible did not survive. Others adopted different strategies and these generated a range of problems that became evident as the ethnographies proceeded. None of the groups reached their goal in an unproblematic fashion and the processes we observed made clear the context of organisational change and complexity. We will therefore devote some time to this in *Chapter 4*.

Service user governors

Introduction

This section covers findings related to the experience of SU governors in NHS FTs, which enables us to explore one aspect of a move from collective to more individualised forms of SUI. This new form of governance enables the involvement of citizens and SUs (among others) in decision-making processes.

National Health Service FTs were first introduced in April 2004, following the *Health and Social Care Act 2003*. Recent reforms to this legislation¹⁰ continue to inform their regulation. Key characteristics include independence as legal entities, financial flexibility and specific governance arrangements based on accountability to local people. Mechanisms for this are via patients and the public becoming members and governors of the trust. FTs refer to their body of governors in a variety of ways. For ease of reading, we will refer to them as 'Council of Governors' (CofG). FTs are authorised, regulated and monitored by an independent regulator, Monitor.⁷¹ In addition, they are overseen by the Care Quality Commission. Each FT has a constitution, which states governance arrangements and accountabilities. Guidance stipulates that an independent person is both the chairperson of CofG and the trust board of directors.

Councils of Governors are made up of:

- elected governors, representing SUs, carers, public members and staff.
- appointed governors, representing local organisations such as other NHS trusts, local authorities and voluntary services.

Governors' term of office is usually 3 years, with the opportunity to be re-elected. A key feature of the governance process is that there is a built-in majority of 'public' governors.

Monitor⁷¹ states that governors are an essential part of the unique governance structure at NHS FTs, providing a 'tangible link' between a trust and the local community it serves. They state that trust governors have a statutory duty to:

- appoint and, if appropriate, remove the chairperson and other non-executive directors, decide their remuneration and allowances, and other terms and conditions of office
- approve the appointment of the chief executive
- appoint and, if appropriate, remove the NHS FT's auditor, and
- receive the NHS FT's annual accounts, any report of the auditor, and the annual report.

In addition:

- In preparing the NHS FT's forward plan, the board of directors must have regard to the views of the board of governors.

Additional powers and duties for the CofG in force from 1 October 2012:

- Governors must decide whether the trust's private patient work would significantly interfere with the trust's principal purpose or performing the trust's other functions.
- The CofG must also approve any proposed increases in non-NHS income of $\geq 5\%$ in any financial year. Approval means that at least half of the governors taking part in the vote agree with the increase.⁷²

At the time of writing, Monitor were in the process of producing revised guidance for NHS FT governors. A draft reference guide had been out for consultation and is referenced throughout this chapter.⁷²

Literature relating to the development of FTs^{73,74} indicates that the models of co-operatives and mutuals heavily influenced developing arrangements. However, those who have examined their work in practice suggest that the prevalent model in use is closer to a stakeholder model.^{75,76} A stakeholder model of ownership is complex compared with, say, co-operatives, owing to a need to respond to a wide range of interests from various constituencies with possibly competing priorities.

Operation and membership of Council of Governors

Council of Governor meetings are public and take place quarterly. There is an option to run part of the meeting in private for consideration of sensitive or confidential issues. Some trusts operate an official governors-only pre-meeting to enable governors to discuss the upcoming agenda and formulate input to the CofG meeting. A system of subgroups and committees to the main CofG operates.

Observations for this study noted the formal nature of CofG meetings operating with a prescribed agenda, dominated by presentations of information from the trust board to governors, supported by dense paperwork circulated prior to the meeting. There were opportunities for questions and comments, invited and mediated by the chairperson. Opportunities for discussion or debate were very limited. In contrast, governor pre-meetings and subcommittees were more informal, with greater scope for discussion and exploration of issues.

The numbers of governors in the three trusts studied were:

- trust A: 39 total, 26 elected (of whom nine are SUs), 13 appointed
- trust B*: 36 total, 25 elected (of whom seven are SUs), 11 appointed
- trust C: 41 total, 27 elected (of whom 12 are SUs), 14 appointed.

[*This trust was a pilot for the 'Implementing recovery through organisational change' (ImROC) initiative which aims to improve SU outcomes and satisfaction levels. Membership entitled the organisation to receive an individually tailored package of expert consultancy, access to specialist, user-led training programmes and materials, and participation in a learning network. Staff attended a 5-day recovery and social inclusion course. (www.imroc.org/our-work/) (accessed 16 April 2013).]

The following analysis is based on research data (observations, scrutiny of minutes and findings from focus groups), plus we also draw upon relevant data from other elements of this study and relevant literature.

Governors' roles

Interviews with chief executives in phase 1 of this study highlighted that a key element of the role of a governor is to hold trust directors 'to account'. However, the meaning and implications of this were unclear. SU governors themselves expressed varying degrees of confusion as to the role of a governor. Governors in trust A talked of not clearly knowing what their duties or responsibilities were, and governors

in trust C highlighted a need to work with the trust with a view to clarifying theirs. Both Wright *et al.*⁷⁵ and Lewis and Hinton⁷⁴ found the same issue in their exploration of decision-making processes within FTs: 'there was a need for consensus between the governors and directors about their respective roles' (Wright *et al.*,⁷⁵ p. 353). One CEO indicated that they had clear ideas around appropriate and inappropriate behaviour in the role of governors:

One or two user governors have got themselves elected on the back of an absolute platform to attack and undermine and that's a shame because it's a misuse of the role, it's not what it's for and to some extent there are plenty of lobby groups out there where that is a better place.

While senior managers cite the ability of governors to hold them to account as meaningful, the SU governors themselves did not share this belief in their agency, although those in trust B were generally more positive about their role. In trust C, governors expressed differing understandings. Although some seemed clear that their role was to input at a strategic level, and were satisfied with this, others described confusion and frustration in relation to the appropriateness of raising 'operational' as opposed to 'strategic' issues at CofG meetings. They stated that the chairperson emphasised that their role was strategic and did not extend to dealing with operational, i.e. service delivery, matters. Observations of meetings noted, however, that operational issues were raised by governors in all three trusts, and received response. Governors in trust B also had different understandings of their roles. Although some sought to use their involvement as a way of directly influencing service delivery, others seemed to position themselves as consultants, providing feedback on services and on the information they received. Respondents in this trust highlighted the value of a robust system of subcommittees that offered opportunities for influence. Two committees in particular, one related to member engagement and one to recovery, were valued as mechanisms for liaising with the wider membership and as forums for discussion and development of ideas. Some cited these as a route for governors to raise operational issues, which could then be reported to the CofG if further action was needed. Subcommittees are typically made up of a selection of governors and, in some cases, trust directors. Research participants from this trust agreed that involvement in the CofG and associated subcommittees was '*more than symbolic . . . it's not tokenistic, tame service user involvement*'. The importance of structures within the trust that facilitate SUI was reported as crucial to this:

I would say that if your question is: does the trust involve us as governors and does it take our opinion into account? Personally, my answer to that question is, yes it does, absolutely. If your question is: does it do so through the meeting of the Council of Governors, and the answer is no.

Trust B, SU governor

The implication here is that it is the status and access to decision-makers in informal settings associated with being a governor who facilitates influence, rather than the formal mechanism of a CofG per se.

In trust C, where frustration was expressed in relation to discouragement of governors raising operational issues at CofG, participants acknowledged that they lacked familiarity with, and clarity about, other mechanisms that exist within the trust to facilitate SU input. Dixon *et al.*⁷³ (p. 87) highlight that it is not only mechanisms for involvement internal to the trust that matter in this regard, but also those in the wider NHS:

The main mechanism for members to hold the FT to account is via the board of governors. This mechanism, which is often quite weak in practice, appears to overshadow other mechanisms for accountability to the local population (i.e. horizontal accountability), such as engagement with members, local involvement networks and overview and scrutiny committees.

Governors' lack of information about, and understanding of, alternative routes for influence echo the experiences identified by some ULOs that struggle to identify where and how they can best interact with a trust within a complex system.

Governors in trusts A and C noted difficulties associated with influencing strategy. An example is the preparation of a draft business plan in trust C that was presented to governors for comment. Although some felt that this was a satisfactory procedure (based on their lack of time for deeper involvement), others expressed concern that the scope for influence was minimal, as key decisions had already been made and incorporated in the draft. The new draft guidance for FT governors notes that although 'Governors can expect to be consulted on the development of Forward Plans for the trust a forward plan can be implemented by a trust without governors' approval,⁷² p. 63). Participants in trust A felt that they had little influence, as decisions were taken by the chairperson and the lead governor.

Monitor requires each FT CofG to elect a 'lead governor'. Guidance states that this is for the purpose of ensuring Monitor can liaise with governors directly should involvement of the chairperson be inappropriate. Each trust has their own job description for their lead governor. In trust B, SU governors made no reference to a lead governor. Rather, they emphasised the value of the subcommittee structure, noting that a range of stakeholders took the lead in various ones, including SU governors. However, in trust C, the way in which the lead governor carried out his role had an impact upon the extent to which SU governors felt they could exert influence. They expressed concern that the lead governor at the time of the research demonstrated allegiance to the trust board and that this influenced how he exercised his role. Access to SU governors within this trust was not easy, partly owing to the 'gatekeeping' role adopted by the lead governor. Researchers' requests to the trust for SU governor contact details were put to the lead governor who, it seemed, had reservations about them being given the opportunity to be involved. Once contact had been established, one SU governor expressed displeasure about the way in which their opportunity to be involved in the research had been mediated by the lead governor. A similar issue with access to SU governors was experienced in trust A, although in this case it was the secretary to the board of governors who was perceived to be playing a gatekeeping role. Researchers experienced no problems when accessing SU governors in trust B.

The new draft guidelines recognise that there has been some confusion surrounding the role of lead governors:

Monitor did not originally intend the person holding this role to 'lead' the Council of Governors or assume greater power or responsibility than other governors. We recognise that many foundation trusts have broadened the original intention of this role and given greater responsibility or power to their 'lead governor'. Every trust may decide how best to structure its own council . . . directors and governors alike should always remember that the council of governors as a whole has responsibilities and power in statute, and not individual governors.

Monitor,⁷² p. 15

Different trusts interpret and operationalise national guidelines in different ways and we found very different experiences among SU governors' experience of involvement in governance in our three case study trusts.

Arguably, the understanding of the role of governor is also influenced by previous experience of other formal organisational processes. The governor body constitutes people with varying backgrounds, experience and knowledge. A system of 'buddying' is suggested within FT guidance, with a view to providing support to governors who may require it.⁷² Although the guidance encourages buddying between governors and non-executive directors, in trust C governors buddied with each other. A SU governor observed that she had deliberately chosen a buddy who had a professional background. Her reasoning was that this person could advise her on strategies for raising issues to ensure that they would be better received. She also suggested that such issues might receive a better response if the buddy raised them, rather than a SU governor. Both FT guidance and SU governors emphasise the importance of relationships. However, the guidance suggests that building relationships will enable governors and non-executive directors 'to understand each other and their respective work better' (Monitor,⁷² p. 69),

whereas buddying was utilised by this SU governor to maximise the influence that she felt able to exert. Relationships can be of different types and designed to pursue different purposes.

Observations in trust C revealed that the SU governor who contributed most frequently, and whose contributions were, on the whole, minuted and actioned, was a longstanding governor with a wealth of experience on other boards and committees. He adopted a formal mode of conduct within meetings, adhering to prescribed processes such as raising issues at suitable times in the agenda, referencing previous minutes where appropriate and making clear requests for action. Many of these contributions were about operational issues, but he was not told that these were inappropriate for CofG meetings. His formal approach and adoption of the behavioural norms regarded as appropriate to such meetings appeared to legitimise his input. This contrasts with the experiences of other SU governors from this trust who were discouraged by the chairperson from raising operational issues. It also contrasts with observations in trust A of an incident where a question was put by a SU governor at a CofG meeting in a somewhat confrontational manner, resulting in a defensive response from managers and signposting to dense paperwork.

Meeting conduct and content

Observations of meetings enabled researchers to note the nature of contributions from SU governors and, hence, what type of role they were playing. On the whole, contributors directed their input to the chairperson and senior managers. The environment was not one of open discussion or debate and we cannot describe these forums as 'deliberative' as this is understood: a process of argumentation that generates proposals, decisions, etc. as a result of an exchange in which all are able to contribute equally (e.g. Fishkin⁷⁷).

In broad terms, SU governors' inputs can be divided into those that focused on specific aspects of the operation of the trust and those that were about the operation of the CofG itself. Inputs related to the operation of the trust tended to focus on specific service delivery issues. At times these were expressed in terms of raising concerns and offers of assistance from SU governors to address them. However, it was notable in trust A that input was more confrontational and challenging in nature. Examples of areas of service delivery focused on by SU governors included: the implementation of a mental health line, telephone answering/messaging issues, complaints procedures, and impacts on SUs of trust expansion/reconfiguration. Contributions relating to the operation of the CofG itself were expressed in a number of ways. There was an example of assurance being sought that support for governors would continue and be delivered in an appropriate way. In addition, suggestions were made about how the CofG and associated subcommittees could operate better, for example by implementation of a timeline for responses to governors; better facilitation of members' meetings; developing links with CCGs; better timetabling of meetings to avoid clashes with other governor commitments, and development of systems to better accommodate SU governors' fluctuating health. At times contributions were couched as requests for further information, for example a request for a report on untoward incidents, along with a request for feedback on the Care Quality Commission's response to trust work and questions posed around the use of trust funds. In trusts A and C, SU governors were observed asking for explanations of information that had been provided in weighty documents, with a governor in trust A being particularly forceful on this issue. They informed the chairperson that they felt it was unreasonable to expect governors to explore dense, technical paperwork in order to find answers to concerns, in this case in relation to the management of risks associated with restructuring of services.

It is striking that the inputs described above are predominantly service delivery and CofG process related. Those that could be construed as 'holding the board to account', such as requests for information on use of trust funds and untoward incidents were fewer in number. However, as the term 'holding to account' has not been defined within legislation,⁷² it is not possible to clearly distinguish what this might entail. This suggests a need for trust boards of directors and governors to ensure that a mutual understanding is developed. Depending on the prevailing culture within a given organisation, this could present a major challenge. Trust boards of directors understand and work with rules and norms that reflect the NHS as a large bureaucracy. The varied backgrounds of governors, along with the institutional factors described

relating to directors, implies a need for thoughtful exploration of terms such as 'hold to account' and 'representing interests' if participation in CofGs are to be a satisfactory experience for all. This exploration could usefully include stakeholders examining openly what drives their approach to decision-making for, as Cairney (p. 76) notes, 'the rules followed implicitly within organisations may even contradict the rules espoused explicitly in their written statements'.⁷⁸

Agenda setting

One way of exerting influence within a formal meeting is the ability to put issues on the agenda. SU governors were asked how this works within the CofGs.

By and large SU governors found it hard to shape agendas. Responses included:

- It is not possible – the agenda is set by the trust.
- They have managed to do so, but only through being tenacious and persistent.
- It might be possible, but they hadn't tried.
- It wasn't necessary as issues were raised and dealt with within subcommittees.

In no case did they refer to the mechanism outlined in their respective trusts' constitutions, all of which are very similar. For example, one states:

A member of the Council of Governors desiring a matter to be included on the agenda, including a formal proposition for discussion and voting on at a meeting, shall make his request in writing to the chair at least 10 Clear Days before the meeting. The request should state whether the item of business is proposed to be transacted in the presence of the public and should include appropriate supporting information. Requests made less than 10 Clear Days before a meeting may be included on the agenda at the discretion of the chair.

One SU governor was observed noting at a CofG meeting that there did not seem to be a mechanism for governors to propose an agenda item. The chairperson's response was that she was welcome to put forward suggestions and they would try to include them. No reference was made to the constitutional position regarding agendas in this response.

Service user governors in all three trusts did not consider that they are actively encouraged to contribute to the agenda of CofG meetings:

It gets circulated around and if we're active enough to disagree with it we can. I don't think we're personally invited to. I don't personally feel we're encouraged to, I think that's a better word, to contribute to it.

Trust B, SU governor

Governors in trust A expressed more dissatisfaction with their relationship to the agenda, with a governor noting that '*The chair makes the decisions*'. In trust C, they could raise their own agenda items in the any other business slot. Differences in opinion emerged in relation to satisfaction with this mechanism. Although some felt that this worked well, others wanted more influence over the main agenda. A trust C governor cited her attempts to ensure that an issue, the trust's mental health telephone line, became a standing item on the agenda:

I feel that every time I have brought it up it's actually been swept completely and utterly under the carpet and I keep raising the banner on it and I shall keep raising the banner on it and I shall not let go.

In trust C, the governor-only pre-meeting was described by SU governors as a vehicle for raising issues related to the main meeting agenda. This was done in two ways. First, by the lead governor who brought

issues from the board on which a response from the CofG was needed. Second, governors themselves raised issues with a view to establishing whether or not the majority agreed that such should be tabled at the main meeting. Governors were asked to volunteer to input to the main meeting, summarising key points agreed. The researcher observed a convivial atmosphere, with governors representing differing constituencies working collaboratively, in a supportive way. One example of an issue on which all governors agreed was to maintain membership of the FT Governors Association when asked by the trust board, via the lead governor, to review this due to the associated costs.

Most trust B participants responded to questions about agenda setting by referring to the subcommittee structure and were positive about their ability to exert influence via this. Particular mention was made of a subcommittee where a SU governor was the chairperson and one related to recovery:

Several committees and subcommittees, they all have their agendas and they have to do their reports and so on, they're then fed onto, onto the agenda . . . committees and things like that, they have their meetings on a regular basis and they have or they make decisions when they want to put something in front of the members. So that then gets ratified in front of the exec.

One trust B participant thought that SU governors are more proactive than other governors and are the most influential in subgroups and committees. However, they recognised that only small numbers of governors are involved regularly, typically between two and four SU governors at each subcommittee meeting. There was a general perception that in order to have influence it was important for governors to take the initiative and 'ask for things'. Although most felt that there were opportunities to join panels and committees, one felt that the subcommittee system was restrictive and wanted to influence more, mentioning recruitment committees in particular. Issues related to involvement in selection/recruitment committees were also raised in both trusts A and C. In both cases concerns were expressed about the process of SU governor involvement. In trust A, one participant robustly expressed their belief in the importance of SU governors having meaningful involvement in these committees. They highlighted the need for back-up plans to ensure that should a SU governor become unwell, a substitute could be found rather than the process proceeding without SU governor involvement. In trust C, discussion focused on mechanisms for membership of the recruitment/selection and remuneration committee. The common understanding was that governors were selected and invited to join by representatives of the trust board. Some dissatisfaction was expressed with one indicating that they would like to join that particular committee but thought they would not be invited to do so.

Relationships

In common with findings from our work with ULOs (see *User-led organisations*, above), the opportunity to develop relationships with trust senior management was seen as central to SUs governors' ability to effect influence. SU governors saw their involvement in this context as a way of 'getting to know people', of having access to named individuals and being able to network with them.

In two of the three trusts (B and C), SU governors highlighted the importance of building relationships with senior managers and interactions with them outside the formal CofG meetings. In trust A, however, relationships between governors and trust management were described in more negative terms, with governors citing major communication problems. The subcommittee process was identified as central to facilitating relationships, along with informal interactions before and after CofG meetings:

I think if you're going to make any sort of headway you've got to make relationships with people, with senior managers, outside the council of Members where it's the 'networking' that is the most important thing, not the formal bit in the meeting.

In terms of making a difference as a service user governor, I think it's more around the access and being able to bend someone's ear.

These responses suggest that it was less their contributions within the formal CofG meetings that enabled influence, as it was the informal conversations that took place around the meetings and the opportunities offered for conversations beyond these particular forums. However, the contrast between what SU governors said about these informal processes and what we observed within the meetings suggested that informal contacts did not make it easier for them to influence the formal decision-making process. What is also unclear is whether relationships (understood here simply as knowing who the person is) with those who are also governors or managers reporting to governors meetings, are sufficiently robust and well focused to enable SU governors to pursue issues that may, for example, derive from their involvement in other user groups. We know that the CEO of one ULO decided to resign from her position as a governor, as she was frustrated by the lack of influence in that role. Arguably, her networking opportunities came from the length of her experience in her role within the ULO, not from her formal status as a governor. And if it is the informal networking that is of value, rather than having a 'position at the table' at which decisions are made, this raises questions about the rationale behind the constitution of FTs being the source of increased accountability to patients and the public.

Service user governors in one trust also talked about the importance of relationships between them as a group. A newly elected SU governor had suggested that they meet together. This would allow them to exchange information and distil which issues were most pertinent to the wider SU population. This indicates awareness of the value of acting as a group, uniting to represent the interests of the constituency of SUs. In writing about FTs in general, Wilmot⁷⁶ questions whether or not such a move would produce the desired results. He comments on the make-up of elected governors and argues that the diversity and lack of expertise means: 'they may well not be able to act in a concerted or focused way, in which case other elements in the ownership will be able to exert power' (p. 164). However, there may be a more substantial shared interest between SU governors in a *mental health* FT compared with those in acute services. In these contexts the diversity of conditions, encompassing those with interests in child health, cancer, coronary and respiratory conditions, and many more, may mitigate more powerfully against SU governors taking a strong, shared position.

Representation

The design of this study included exploring SU governors as an individualised form of involvement, rather than the collective model of ULOs. The issue of representation arose within this context as it did in other parts of the study and has in work on citizen participation generally.⁷⁹ We have noted the need to distinguish between representation that is democratic, statistical or based on interests.⁸⁰ Below we consider this in relation to our work with SU governors.

Service user governors in trusts B and C discussed the extent to which they felt they represented other SUs. This did not emerge in discussions with trust A governors. Views on this issue were mixed. Some described a sense of duty to those who had elected them, along with concerns and frustration when they felt that they had failed to represent those who had voted for them, talking in terms of 'letting them down'. Others felt less exercised on this issue with some expressing doubt about whether or not they could adequately represent other SUs. One concluded:

As far as governors there is a large selection bias. By definition to get elected as governor you have to be articulate and you have to be well. So I am never really sure whether I am representing anybody else.

In contrast, another noted that SU governors themselves are a diverse group, with varied opinions and politics, which makes them representative of the wider population of SUs. There was an additional level of complexity for some governors who were active members of ULOs. Focus group discussions highlighted differences in opinions on whether or not they were representatives of members of these organisation in their role as governors. Most thought it was important to use information they had from their groups to inform their practice as governors.

These findings illustrate how different meanings of representation become blurred. Some governors are talking in terms of 'democratic representation', where the representatives may not share any of the characteristics of those who elect them, but are accountable to them, whereas others are framing the discussion in terms of 'statistical representation' or 'typicality'.

A further complication is an expectation that SU governors, by virtue of their position within trust governance, might be considered to in some way 'represent' the trust. This was evident in the way a governor from trust B explored some ambivalence about representing SUs and working on behalf of the trust:

As service user governor you have got to keep that barrier between yourself and the organisation. If you don't do that then you become part of the organisation itself and service user governors are not there to do that { . . . } We might represent things to the trust but I've never felt that I'm representing the trust.

Wright *et al.*⁷⁵ discuss the issue of governors' relationship to the trust in different but related terms. They highlight that there is a danger that governors 'can become captured by the organization' (p. 364). As mentioned earlier, SU governors in trust C indicated unease with the situation related to the then-lead governor who, in their perception, had strong allegiances to the trust board of directors. They felt that this caused him to attempt to use his influence with governors to encourage them to comply with board wishes. Above (see *Managers', commissioners' and clinicians' views on user involvement*), we discussed the 'stakeholder discourse' associated with SUI. The issues raised above illustrate tensions associated with this in relation to representation. SU governors could be said to be representing one set of stakeholder interests while at the same time being expected to work collaboratively with other stakeholders, recognising different interests, to the benefit of the organisation as a whole.

The ambiguity that surrounds the issue of representation has been picked up by Monitor.⁷² They note that the *Health and Social Care Act 2012* puts a duty on governors to represent the interests of FT members and the public, but notes that the meaning of 'representing interests' is not defined in legislation. The draft document seeks to outline key principles to guide governors in fulfilling this duty. The notion of distinguishing between representing the 'public interest' and 'the public' is not a new one as it was evident in critiques of the 'unrepresentative' nature of community health councils (CHCs).⁶⁵ CHCs were constituted to act as representatives of the 'public interest' in relation to the NHS, but the criticism that they were not 'representative' in terms of the characteristics of their members was one factor leading to their demise.

As well as the need for greater clarity around the meanings of representation, there are also practical issues that are important in enabling representation in practice. If SU governors are expected to act as representatives of the wider membership, what mechanisms and resources are available to enable them to do this? This varied in the three trusts. In one trust, the work of a subgroup of the CofG was dedicated to maintaining such contact, whereas this mechanism was not so well developed in the others. An associated issue is the extent to which governors can give of their time to implement greater contact with their constituents.

Impact

Service user governors have differing views about the level of input, influence and ultimately impact they have or expect. The formal approach taken to CofG meeting procedure was considered unhelpful by research participants in relation to enabling influence. The dense, often technical paperwork associated with the governor role does not always enable information to be located or discussed as some SU governors would like. Observations of both councils within trusts A and C noted SU governors asking questions on issues to which the response from trust management was direction to long, weighty documents. In both cases, there was an inference from directors that the governors were deficient in some way and were in need of 'help' to read the documents. As noted earlier, a SU governor in trust A was

observed pointing out that the document itself was the problem. His query related to risks associated with trust restructuring. Following an exchange between the SU governor and trust director, another governor interjected with 'can you just tell us what the risks are instead of having them buried in the document'. The combination of dense paperwork and formal presentations with short question-and-answer sessions was comfortable for a few governors but did not suit others or facilitate their ability to hold the trust to account. The less formal, more discursive approach taken within subcommittees seemed to lend itself better to exploration and discussion of issues.

Our findings reflect evaluations of other FT governance processes (not specifically mental health trusts). Wright *et al.*⁷⁵ identify positive outcomes as a result of patient and public governors questioning trust services and emphasising patient experience. However, they and others^{73,76} question the degree to which governors can influence the management of trusts, noting that ultimately accountabilities are upwards, towards regulators and the Department of Health, which complicates the notion of social ownership. Wilmot⁷⁶ (p. 166) concludes:

The co-operative model and stakeholder model both have serious limitations as ways of understanding the foundation trust, because the ends that it is primarily required to meet are those of the Department of Health. Its members are constrained by that end, as it must be their end also. This is not a problem for the organisational stakeholders because as state bodies they share that purpose . . . the foundation trust will in fact still depend for its legitimacy on central state involvement, rather than on its local links.

We highlight key issues arising from this section of the research in *Chapter 4*.

Personalisation

Introduction

As we noted in *Chapter 1*, personal budgets in social care have been in existence for 7 years now and the pilot in health care is 3 years old. Different terminology has been used to describe these, including SDS, coproduction and individual/independent budgets. All of these terms are said to describe 'a different relation' between those who receive support and those who provide it, with more power being transferred to the former.

As we have seen above (see *Managers', commissioners and clinicians' views on user involvement*), when interviews were carried out with senior staff there was little actual experience of the impact of personalisation as a mechanism for user involvement. Thus, interview responses often reflected anticipated benefits and difficulties rather than actual experience. These responses embodied a range of views from irrelevant to empowering. One view was that using people with lived experience to carry out support planning represented major cultural change and 'shifting power to the individual'. But others expressed concerns in relation to issues of quality, risk, safeguarding and monitoring:

It's that individual employing that personal assistant, and if they let them down then it's the challenge of who will support in the absence if they decide they're not going to do it any more, which I have observed experiences of that.

Team leader

There was also a view that the system could be confusing and created a need for support:

If they aren't able to, or you know perhaps the capacity to understand exactly what the process is erm whether they meet the erm the FACS level for entry into services or not. How that's worked out, how that's understood. I think it could be difficult for them.

Team leader

Personalisation was also identified as a site of tension between the principles of SUI and evidence-based policy and practice. A manager talked of managing risk and the dilution of professional expertise, whereas a commissioner asked 'who says what works?'. But a different focus for tension was identified by a team leader who said:

Now, if someone . . . has their personalisation package in place and they are doing well and suddenly someone decides that they've got to manage without half their package, for financial reasons, they are entirely alone in fighting that challenge and saying 'no'. Whereas previously if they'd said 'we're going to cut the staffing of our day centre by half', you would have had a group of people at a meeting protesting about that because those people shared that resource and that's what happened when they first started to close it down. So in some ways erm losing the collective service user identity disempowers but in other ways it empowers people as individuals. This is the sort of trade off.

Recruiting

We saw above that personal budgets were discussed largely in anticipation by senior staff. Our efforts to recruit people in receipt of personal budgets met with very modest success with the result that we were able to run only one focus group in each trust. We consider this to be a finding rather than a limitation of our method especially in light of government targets that 70% of recipients of health and social care services should have personal budgets by the end of this parliament (this figure was originally 100%). We will therefore take some time to consider the situation with personalisation in our three trusts.

Suggestions that there may be difficulties in recruiting participants for the focus groups were alluded to early on in the research period during our observations of ULOs. For example during observations of one group it was noted that there was many a discussion about budgets, allowances and financial matters in general. These discussions were often marked by confusion, uncertainty, misunderstandings and arguments. Group members often chatted about the differences and similarities between payments they received including social care personal budgets, disability living allowances, employment and support allowance, direct payments and universal credit. It was clear during these discussions that each member of the group had experience in receiving a form of payment but that they were becoming increasingly worried about the likelihood of their benefits getting cut or changing and that they would have to be reassessed in order to qualify for a new form of payment. Assessments to determine an individual's personal health budget is completed through a FACS assessment but, again, members rarely referred to it as such, while others simply did not know about this form of assessment. At one of our focus groups this point was highlighted:

Man: *We don't even know, what's the criteria to get direct payments? How are you entitled to get direct payments?*

Ooh that's secret, they go into a little room, no they do, they have a thing called a funding panel and they go in there and they decide.

Man: *Who decides on the amount of hours you get?*

The funding panel.

Interviewer: *I can't answer that in detail I mean assuming that the budgets that you have are social care budgets there is something called FACS, the fair access to direct care criteria. Have you come across this?*

Man: *No.*

Interviewer: They are a set of criteria that are used to assess people's level of need and depending on where you come on those criteria it, it decides whether, whether you are entitled to a service or not and you have to be pretty, have pretty significant needs before you actually meet the criteria.

I know the one you mean, yea, they're listed so you can't, it has to be, you have to be sort of highly likely or something just to maim, I can't remember their wording, to, for, for your independence to be at risk.

Interviewer: That's right, yea, yea.

So, you know, to end up in hospital of whatever institutions.

In recruiting to the focus groups that did take place, this confusion was also evident. The eligibility criterion was to be in receipt of a personal budget in social or health care, but individuals did not know whether or not the monies they received did indeed constitute personal budgets. Some staff informed us that some SUs did have personal budgets but had not been informed of this. Finally, many SUs wanted to participate in the focus groups because they thought this would be a route to accessing personalised forms of care. In responding to advertisements about the focus groups, potential participants often asked questions such as: What is a personal budget? Can you tell me where I can get a personal budget? If I come along do I get a personal budget?

The focus groups

One focus group was convened predominately with individuals associated with one ULO, whereas finding individuals with personal budgets from the other groups turned up limited results and hence the groups were small. Furthermore, in two trusts the discussion hinged almost entirely on the FACS assessments and the different criteria that individuals had to fulfil in order to be able to qualify for payments. However, these discussions were typically in similar anecdotal form, with individuals referring to high thresholds and stressful assessments. At one of our focus groups a participant referred to the stress involved with assessments:

M1: Yes, yes I did. I'm a champion on the user group and involved in trying to get users' needs identified in a way. Because what I felt was that there was a lot of bureaucracy. Key worker session I mean they came into my place and using up all that valuable time in the paperwork. Another key worker session. Another risk assessment, I said, goodness, no, I can't work like this, you're wasting all this time in the key worker risk assessment, this assessment, we're not doing any work here. Forget it.

Likewise at a different focus group, the lack of understanding over the name of the assessment and the stress involved was discussed:

M2 (carer): I think what you might find is they use these assessments as a means of delaying. To give you a case in point, I forget the technical term of the assessment, but they sent me somebody down to find out what my brother can do in terms of cooking, cleaning, washing, etc., I don't know what the technical term of that is . . . A woman . . .

Interviewer: Is it a FACS assessment?

M2 (carer): A what?

Interviewer: A FACS assessment.

M1: A Fair Access to Care assessment.

M2: *I don't know what it is.*

Interviewer: *Oh OK, sorry.*

The carer went on to delineate the endless visits he had endured, the intrusive nature of the questions including questions about his own bank account and the long delays in receiving any replies to enquiries. It should be noted that this carer was doing this on behalf of his brother and he was clear that his brother, the SU, could not have done it himself.

Our final focus group was held at one of our ULOs – arts group. They were holding a weekly creative workshop and participants were using their personal budgets to pay for it. Once again, there was much talk of the assessment process and how difficult it had been to secure any money at all. For most of the participants in the workshop the payments for this were the sole monies they were receiving. For this, most of them were grateful. These participants mostly knew each other from other mental health services and so they were using their personal budgets in a collective or pooled fashion and the social element of the occasion was clearly important.

Conclusions

The picture that emerges here is one of frustration and bewilderment, and we detected this among front-line staff as well as SUs. The charitable conclusion with respect to personalisation is that it is too early to tell. Less generously, it might be concluded that the rhetoric outstrips the reality. Furthermore, in mental health the standard disability model of a personal assistant is less relevant, recipients are getting small amounts of money that do not make up for closure of other services such as day centres, while at the same time collective forms of provision are in some cases being reclaimed as we found with the SU governors in trust C.

Chapter 4 Discussion

This study was designed to explore the impact that user involvement in mental health has had and continues to have. It also sought to understand interactions between the changing landscape of mental health services and policy, and the way in which SUI is practised, in particular to consider whether or not we are seeing a shift from collective involvement via user groups to more individualised forms of involvement. In this discussion we reflect on our evidence in relation to both these issues.

The involvement of 'ordinary' service users

One of the spurs to this research was the dearth of evidence in the literature about whether user involvement in mental health services has any impact. The results of our survey indicate that SUI is now more commonplace among 'ordinary' SUs than had previously been thought and that those who participate in involvement activities think it is having a positive impact. This is the first time this has been demonstrated and it is important as previous work⁶⁰ suggested that decision-makers believe that 'ordinary' users have no interest in involvement activities, partly because it is believed they have nothing to complain about. We saw also that front-line staff were mostly supportive of user involvement activities and that they particularly welcomed user involvement in training. The prediction that social workers would be more positive than those with a nursing background was borne out and is consistent with the work of Kent and Read,⁴⁹ although the context of the two studies is quite different.

Involvement of a deeper kind and the legacy of institutional norms

If the results of the survey suggested that many SUs now have some participation in involvement activities and that this is regarded by them as having a positive impact, when we look at more in-depth forms of involvement, we see again an acceptance of these as part of the terrain of mental health, but in a context of organisational change and complexity. This context is so important that the next section of this discussion will be devoted to it specifically. It frequently pulls SUs and their organisations in many directions at once and exerts demands that risk outstripping the resources of both individuals and groups. Furthermore, although we found reason to be optimistic about the current state of SUI, we also found limits on what could be achieved and what was permitted or sanctioned in terms of norms of behaviour and involvement 'style'. Metro group constitutes a limit case for current involvement strategies to the extent that it refused to give up its 'old style' ways of constituting itself and working. Similarly, the CEO of trust B regarded the 'confrontational' style of some user governors as unacceptable. Following a discussion of organisational complexity and change we shall consider what these results tell us about the nature of the contemporary user movement in mental health in England.

Change and complexity: seeking impact in a dynamic environment

In our original proposal we noted that the context in which this research would be undertaken was one characterised by significant change. This was, in part, a reason for proposing the work: we sought to understand how systemic changes within the NHS and social care were impacting the comparative emphasis on individual or collective models of user involvement. But we also noted that changes that were not primarily focused on user involvement (most notably the move to CCGs), were likely to create an unstable environment within which we would be exploring what impact the established and newer user groups, and other mechanisms for involvement, were able to achieve.

Arguably, change is a constant within health and social care systems. The NHS has gone through a series of significant restructurings since the *National Health Service and Community Care Act 1990*, and within that period there have been major legislative and practice developments that have directly impacted on what is referred to as 'PPI' within the NHS as a whole. It would have been hard to identify any point within this period when there was a completely stable environment providing a context for linear development of impact from the different ways in which SUs have been involved in service development, delivery and policy-making.

In exploring the particular characteristics of the dynamic context that have impacted the experiences of user groups and user governors, we do not consider this context as simply external to the operation of the mechanisms and strategies for involvement. Rather we understand SUI and the relationships and interactions generated through this as one aspect of this dynamic. In terms of impact we need to understand how the involvement of SUs is implicated in change and complexity.

Evolving cycles of involvement?

... complex systems are not likely to be replicated precisely the next time the system repeats a process. The process is evolutionary and changing. So the collective user voice in social care, or changing provider behaviour, can influence policy more than policy-makers first expect.

Haynes,⁸¹ p. 200

In this quote Haynes not only characterises the non-linearity of change within complex systems, but also identifies three of the groups of actors that interact in the change process: *SUs* – through collective voice; *service providers* – through the decisions they make and the behaviour this gives rise to; and *policy makers* – who perhaps thought they were in charge of the change process. Each of these sets of actors is of significance in this study, but so too is the group that Haynes⁸¹ does not identify: the commissioners.

If we look back to the experience of SU groups in the early 1990s, at a time when the 'purchaser-provider split' had first been introduced, Barnes⁶³ (pp. 85–6) identified a number of dilemmas facing user activists as they sought to achieve change in service systems:

1. The potential for energies to be dissipated as the number of bodies involved in governance processes and the number of forums in which decisions might be made increased, and as evidence of competition for influence between purchasers and providers emerged.
2. The danger of becoming reactive to official agendas rather than developing and promoting their own.
3. Dangers associated with being drawn into more formal relationships with statutory authorities rather than maintaining their independence.
4. A consumerist philosophy that legitimated user involvement through the pursuit of individual consumer rights rather than collective action to secure social change.

We have seen evidence for all of these dilemmas within the contemporary experience of the groups we have observed in this research (see *Chapter 3, User-led organisations*). But we cannot simply conclude that we are seeing a rerun of the dilemmas generated for user groups by the latest phase of restructuring towards CCGs. The influence exerted by user groups has been part of the process of evolution that we are observing, not least in the impact of the disability movement on the shift towards personalisation and the introduction of personal budgets. More broadly, the position of SUs within systems of governance is much more established than was the case in the 1990s. This, in turn, may make it less likely that competitiveness between commissioners and providers will turn on 'playing the user card'⁶¹ as a way of claiming the moral high ground.

Hence, in considering aspects of the current environment we need to understand the role of service user involvement in creating as well as being subject to these contexts. We reflect on key changes under

three headings: system changes; changes to service models; and, changes to PPI and to SUI. A cross-cutting and significant further factor is the impact of budget reductions within the mental health system.

System changes

The shift from PCTs to CCGs was a transitional process at the time of this research. There was uncertainty about what this would mean in practice and no direct experience of its impact. Although our focus was on the three trusts as service providers, we included six commissioners among our senior interviews and issues relating to processes and impacts of commissioning also arose in case studies.

Some interview responses suggested possibilities for user influence in the context of the unsettling of relationships generated by commissioning changes and the challenge to 'provider power'. But this was a minority view and the experience of ULOs did not, by and large, support an interpretation that the instability in the system was proving beneficial to user groups. Rather there was evidence of uncertainty about the emergent mechanisms and of energies being directed in forums that were unable to deliver the objectives sought. In the case of county group (trust C) the separation between commissioning forums and those concerned with implementing service changes was being experienced as a way of limiting opportunities for involvement and influence. There was uncertainty about the appropriateness of a forum set up to enable dialogue between SUs and commissioners being used to promote practices in a provider context that were sympathetic to the involvement of SUs. However, exclusion from the relevant provider forums meant that this appeared the only context in which action could be taken. Some eventual success in securing access to forums through which implementation was taking place potentially meant taking part in a number of different fora based around the geographical areas that structured service delivery. As we develop below, that, in turn, creates challenges because of the sheer numbers of spaces in which user groups and ULOs have the possibility of seeking influence.

Interview responses indicating the potential of user involvement to strengthen the credibility of the commissioning process via dialogic mechanisms enabling wide stakeholder involvement were, at this stage, aspirational. A pessimistic view that in practice professional (clinical), provider (trust boards) and financial interests would outweigh any SU interests in determining commissioning decisions was reinforced by a sense that much of the current decision-making concerned decommissioning in the context of budget cuts. A lack of knowledge and expertise in the technical aspects of commissioning was also considered likely to inhibit users' ability to influence this process. This suggests that a 'moral imperative' is no longer seen as a source of user influence, rather SUs need to develop the skills to play the game more effectively than other interest groups. A more optimistic take was that if it was possible for user groups to come together and present a united stand this would be helpful to their cause. However, there was little evidence of any of the groups that were the subject of our case studies being involved in consultations or more dialogic mechanisms in relation to commissioning. The county group did have a profile in the context of a commissioning forum, but as we have seen the key goal it was pursuing related to service provision that had been agreed before the relevant forum was established. The arts group (trust A), which had positioned itself as a provider of services that were responsive to users because they were user led, was reflecting on how to reconcile what users wanted with what commissioners were likely to buy.

Some ambivalent views were expressed in senior interviews about the relationships between SUI and commissioning. One perspective was that commissioners were too distanced from the immediate feedback from users to the services they received to understand how users felt about them. This distancing was likely to increase if personalisation led to an expansion of 'microcommissioners'. On the other hand there was also a view that feedback given at the time of service use would be constrained by a feeling that 'someone was breathing over your shoulder', and another view that commissioning should be forward looking and that current or former experiences of existing SUs had limited relevance to decisions about future services. However, there was also a suggestion that commissioners were not very good at reaching out to a wide range of people, particularly those who were most isolated or excluded, so it is not clear how they might access those who are not already engaged.

One possible response to this might be through user-led research. One commissioner spoke very positively about the benefits of user involvement in research and we have considered above (see *Chapter 3, User-led organisations*) the increased focus on research as a mechanism for involvement. However, neither the research group (trust C) nor the evaluation group (trust B), the two groups that focused on research as a mechanism for SUI, were actively engaged in research that directly related to the commissioning process. ULOs may be better at reaching currently unengaged SUs to research their views in order to inform commissioning decisions, but there was no evidence that they were being supported to act in this way.

The other dimension of the move to CCGs is the developments taking place in provider organisations and in the provider market. Again, there was limited experience of this at the time we undertook the empirical work for this research, but there were some indications of the way this might interact with user groups and user involvement more generally. We noted above that one of our case study groups (arts group) had positioned itself as a service provider. However, it had had to downsize and reduce the services it provided as a consequence of losing funding following cuts and the introduction of personalisation. The size of personal budgets and delay in implementation meant that the loss of grant funding was not compensated by individual purchasing decisions made by SUs. At the same time, there had been an increase in demand for its services following day centre closures. This is a pattern that has been seen more broadly, as the aspirational increase in community resources envisaged to follow from personalisation has not accompanied the rate at which day centres have been closed.⁸²

Some interviewees identified other provider developments with implications for relationships between user groups and trusts. One consequence of market development is that trusts are bidding to provide services outwith their original geographical area. For example, the rural trust is now providing Child and Adolescent Mental Health Services (CAMHS) services in another county and other specialist services in London. This leads not only to an increase in the size of the organisation, but to a weakening of the identification between place, service and SUs. The significance of this was reinforced during discussions in phase 3 of the research. And as well as an expansionism initiated by mental health trusts seeking to provide services in other areas, one of our trusts (trust A) was involved in a consultation that could lead to incorporation within a much broader clinical configuration. An early example of potential impacts of this was the fate of the Nottingham Advocacy Group – one of the earliest place-based mental health user groups to be established – when faced by trust merger and expansion. What had been a vibrant and respected ULO lost not only its resources, but also its identity as an independent advocacy organisation.⁸³

We did not encounter quite this effect in our three trusts, but we have seen the difficulties experienced by user groups based in one geographical area seeking to influence policies and practices of an organisation that operates across a much wider area. This is particularly evident in trust C, as this encompasses not only two county councils and one city council (i.e. three different social services authorities) but also an area of about 1500 square miles. In this context, not only are there multiple service locations and decision-making fora to which user groups might aspire to relate, but also there are huge practical and logistical problems associated with enabling SUs to meet, both among themselves and with officials. Although the two metropolitan trusts do not cover such a wide geographical area they do encompass different boroughs and hence social services authorities, and this is reflected in the structuring of board membership with SU governors elected to represent different geographical constituencies.

Another response to this aspect of complexity is to emphasise the importance of personal relationships as a means to secure support for SUI at different locations within the system, to enable connections to be made and to facilitate impact. The importance of establishing effective working relationships was identified in all the user group and user governor case studies. This reflects insights from complexity theory that complex systems do not proceed in a linear manner according to the specific conditions in operation at any one time, but that human actors have the ability to interfere with and thus change the path that a system takes.⁸¹ We observed instances where such relationships were able to create 'spaces for change'.⁸⁴ Thus, the CEO of the arts group put considerable effort into establishing good working relationships with service providers and considered that this was important to ensuring support for the organisation.

However, such relationships are not immune from the impact of power relationships within the system and of external contingencies that can, in this instance, be understood to reinforce the inequalities of power experienced by SUs, both individually and collectively, in their interactions with the mental health system. However good the relationships that the CEO was able to establish, this was not capable of generating the level of funding needed to secure the work they aimed to carry out. And in the research group case, although there was evidence of a good working relationship between the SUI coordinator and research director, this did not automatically mean that he could offer complete support for research group's objectives, as he needed to take into account other stakeholder interests that reflected powerful interests within the trust.

Service models

One factor shaping the design of this research was the implementation of personalisation and the anticipated impact of this on the means by which SUs can influence services. Personalisation has been hailed as something that would generate transformative impacts on the relationships between providers and users of services. Alan Johnson, then-Secretary of State for Health, declared that personalisation represents 'a major transformation of power from the State to the Citizen'.

As we have seen in *Chapter 3* (see *Personalisation*), if it is to have this impact then there is still a considerable distance to travel, although some of those interviewed in phase 1 of this research were anticipating significant changes as a result of 'empowering' individual SUs to choose their own services. At this stage we can see little likelihood that the individual choices made by SUs in receipt of personal budgets can have any profound impact on mental health services. Indeed, and as demonstrated by the experience of the arts group and research looking specifically at the effect of personal budgets on day services,⁸² rather than stimulating the development of community resources responding to user choices, personal budgets have had a negative effect on the availability of small community services. This effect is rather unsurprising to those who have retained a critical perspective on the potential of consumer-based models of user involvement to secure the kind of transformation that is claimed above and which reflects the significance of shared experience as well as individual needs (for example see Barnes⁸⁵).

Service user groups have always had a role in supporting people who live with mental health difficulties and the value of shared experience in this, as well as in securing change within the mental health system, has long been recognised.²¹ Even when peer support is not the direct aim of the groups concerned (e.g. the research group in this study), understanding vulnerabilities, and developing ways of working that can accommodate and reduce these, are necessary to effective working within user groups that enable people to experience the benefits of taking part. Peer support was also linked with the evolution of the recovery philosophy and in one trust the development of a 'recovery college' was cited as a good example of coproduction in action. However, concern was also expressed about peer support being used to obscure service cuts and the danger that peer support workers could be marginalised within large teams of professionals.

The recovery model is one that reflects 'responsible public' and 'therapeutic' involvement discourses. It is a very different model from that of personalisation, and arguably the transformations – in terms of relationships between mental health professionals and SUs that recovery implies – are both more demanding and more creative than the shaping of microcommissioners. However, our study suggested that there was no role for user groups in such developments. None of the groups we studied identified goals relating to peer support in the context of recovery rather than personalisation, and senior interviews suggested that user involvement in the context of a recovery-oriented way of working was something that was being driven by professionals.

In addition to changes in service philosophy, service redesign was under way in trust C and trust A was in an uncertain position vis-à-vis a merger with other trusts. If the latter merger did take place it was anticipated to be unhelpful in terms of SUI because of the size of the resultant trust and the distance between users and what they seek to influence. Interviewees in trust C recognised that the move to bring

together assessment and treatment services had interfered with the development of good practices in SUI, and that the trust had failed to enable such involvement in the process of developing ideas. The county group case study was focused precisely on this lack and how it might be resolved.

Changes in service user involvement

Part of the overall context for this study is the shift from a situation in which SUI was seen as a radical, progressive initiative on the part of innovative service providers and SU groups, to a situation in which it is official policy, where some groups are well established and have been in operation for more than 20 years and in which it has become something that is 'done by' mental health professionals and managers. One consequence of that has been not only an increase in the number of user groups in operation, but also a diversification in the contexts in which involvement takes place. In the interviews with senior managers and professionals we identified the following contexts for and types of involvement that were mentioned:

1. user groups
2. user governors
3. commissioner-initiated stakeholder forums
4. consumer feedback via postcards, surveys, ICT
5. service-based forums
6. research and user-focused monitoring and evaluation
7. recruitment
8. training
9. peer support
10. user-provided services
11. SUI via third-sector organisations (not necessarily user led)
12. PALS
13. PPI forums, then LINks, and with Healthwatch just emerging
14. GP practice groups
15. locality-based health action groups.

This list reflects not only the success of SUs in developing and expanding those areas in which they have sought influence, but also the shifting government policy in relation to PPI in health services generally, the changes in service philosophy that we considered above, and the emergence of information and communication technologies as media through which SUI and PPI can be facilitated. It suggests that the decisions that ULOs and individual SUs need to make about strategies to achieve change are more complicated than whether to work with and within the system or to maintain independence and work outside formal mechanisms. They also relate to what might be considered preferred mechanisms for change, for example to seek to impact on attitudes and behaviours through training mental health professionals or to impact on strategic decision-making via trust boards.

A focus on attitudinal and behaviour change via training or other activities intended to impact the way in which professionals think about mental health SUs and ways of working with them reflects not only the importance of the front-line interactions between providers and SUs, but also that institutional change can be prompted by the everyday actions of individuals in their work. This reflects the insights offered by Lipsky⁸⁶ in his study of 'street-level bureaucrats' and subsequent analyses of the way in which front-line workers may 'subvert' 'official' policy as they interpret and reinterpret policy through their own personal and professional values, identities and commitments, and through negotiations with SUs.³⁰

Our original interest in the impact of changes in the balance between individual and collective involvement thus needs to be modified to reflect what is a much more complex picture. User objectives have always been focused both on enabling people to have greater say in individual decisions about care and treatment, and about the policies and practices shaping service design at a collective level. Some have also had much broader objectives relating to the way in which 'mental illness' is understood and to the way in which people with a diagnosis of mental illness are excluded as a consequence.^{21,64} What we are observing

in the current context is the way in which SUI is now viewed as integral to many of the processes necessary to the conduct of trust business, as well as being encompassed within both individual and collective service delivery practice. That does not mean that objectives have been realised or that working with SUs rather than delivering services to them is common practice. It does mean that user involvement itself is characterised by a complexity that both users and workers sometimes struggle to negotiate.

The interviews with senior staff reflect certain aspects of the complexity that this diversity gives rise to and the experiences of our six user groups reflect other aspects of this. From the commissioner and provider perspective complexity encompasses both the sheer amount of user feedback without the corresponding systems that would enable learning and change to result, and the diversity of types of user input, the ways in which this is expressed and the ideas and positions reflected by this. Thus, not only are mechanisms – such as trust boards with opportunities for user governors to have a voice – seen to have been introduced on top of locally developed forums that enable users to have a say at the level of specific services, the oppositional behaviour of some user governors was identified as inappropriate to this context for involvement. Similarly, inputs based on personal experience and accounts of the impact of poor or insensitive treatment, which are useful in the context of staff training in order to help them understand the experience of living with mental health difficulties and of using services, are considered out of order in the context of, for example, user involvement in recruitment processes. What is missing is a clear framework within which understandings can be developed of how different types of input are appropriate in different contexts.

The situation in trust B can be understood to reflect the trust's desire to manage what might otherwise be an 'unruly' process of SUI. In committing itself to support and develop SUI, this trust had developed a managed process that provided a structure within which there was clarity about the opportunities for users to have their say, and indications that they could see impacts from their involvement. What is less clear is the space that exists for autonomous action by SUs and how they might challenge and express opposition to trust actions. Thus, we were able to identify only one autonomous user group for study in this trust. Evaluation group is a well-established group that has focused its work on training, evaluation and research because of experience indicating this was the best way to exert influence. It remains user led, but, as we have seen (see *Chapter 3, User-led organisations*), it is well integrated within trust processes to obtain feedback on services, although clearly set apart from involvement in ongoing governance processes.

It is interesting to compare the way in which the evaluation group has developed a role and identity as an organisation that can provide user-focused evaluation of service developments, with the way in which the research group is seeking to influence research through impacting on the way in which both in-house and hosted studies are conducted. The research group's objective was focused on internal governance processes (in that case, research governance) and it is perhaps for this reason that this provoked a degree of conflict between the interests of SUs in ensuring research conduct that, at least, did not harm user interests: the trust's interests in securing income from research, and academic interests in conducting research and generating publications from this. In this instance, it was precisely the strategy of working with procedures and rules that caused the tension because the objective sought specifically to modify those rules. Evaluation group's activities also highlighted the way in which user input can generate different responses at different places within the system. It was front-line operational managers who felt ambivalent about their work, whereas senior managers welcomed it.

One particular focus of this study for seeking to understand the increasingly complex terrain of SUI per se was our focus on the roles and experiences of user governors. We found evidence of considerable difference between the three trusts in terms of such experiences. The picture in trust A suggests that there is a long way to go to establish a process by which SUs might consider that becoming a user governor is an effective route towards achieving user focused change. In both of the other two trusts the picture is more optimistic, although the situation in trust B was regarded more positively overall than was the case in trust C. From the perspective of this discussion of the challenges generated by the inherent complexity of the NHS and the particular change processes under way during the study, we can highlight a number

of features from our analysis that indicate it is not sufficient to see this as a way of promoting individual rather than collective involvement.

In trust B, the development of practices relating to user governors is part of an overall trust-led strategy for SUI, whereas in trust A the requirement to introduce these mechanisms was described by some in terms of an unwelcome additional layer on top of locally determined arrangements. In both trusts B and C it was evident that the significance of the introduction of user governors goes beyond the role they play in Board of Governors meetings. User governors in both places described not only a series of working groups and special events that were opportunities for governors to contribute to policy-making, but also the significance of the informal networking opportunities opened up by these roles. This created the tensions evident in other contexts for involvement: on the one hand SUs were faced with considerable demands on their time and energies as a range of contexts for involvement opened up, but they also had opportunities to develop the type of 'informal' relationships considered to be as important (if not more so) than formal mechanisms as a means to influence change. And one type of relationship that was being developed was that *between* user governors: in trust C during the course of the research there were moves to increase effectiveness through closer collaboration among user governors.

The creation of user governors who are elected to these positions also raises the issue of user representation in a particular way. Election offers a formal legitimacy to the role of representative without being accompanied by clear systems by which that accountability can be exercised – other than in terms of whether or not people are re-elected. Thus, user governors who took part in focus groups were aware of their responsibilities as representatives, but were often uncertain about how they could exercise this (in the case of those who had no contact with user groups or, in some cases, current experience of service use) or how it related to their involvement with specific user groups. One user governor in trust C, who also had a lead role in the county group, distinguished her representational role as governor from her role within the county group by suggesting that, as a governor, she should seek to represent all SUs, not only county group members. Her personal experience of seeking to combine her two roles, while also keeping them apart, reflects a systemic tension in terms of the lack of clarity in the way in which representation has been sought from user governors (see *Chapter 3, Service user governors*). Arguably an opportunity to link SUI through user groups with user representation on boards of governors has been lost because of the need to work within the constitution for FTs as set out nationally. The county group governor decided to resign as a governor towards the end of the research period. This reflected her frustration about being able to achieve influence through this route, as well as the challenges of trying to combine different roles. While in principle the opportunity to influence trust strategy through involvement as a governor is different from other contexts in which operational issues are more of a focus, many user governors found this distinction a hard one to draw and the lack of a coherent link between SUI at operational and strategic level problematic in terms of ensuring consistency of influence throughout the system.

Although it is clear that contemporary changes in the architecture of the NHS were impacting SUI in these three trusts, we cannot simply argue that such involvement is being impacted by these changes. Rather we need to understand the increasing complexity of involvement as part of the picture that is presenting challenges for SUs in terms of decisions about strategies to adopt, and for managers who can be seen as having supported increasing diversity of input without the systems to respond to the results of this. We now narrow our focus and consider what we have learned about the contemporary SU movement in England and its interaction with decision-makers.

The enduring significance of collective action

The experience of the user groups we observed and of the SU governors suggests that the mental health SU movement has changed since the 1990s, but continues to exist as SUs occupy new spaces and take on new identities. Official adoption of user involvement has made it harder to sustain an oppositional stance and retain a position as an accepted group with which to consult and debate. Some groups, such as the evaluation group have adapted to find a new way of operating that receives recognition from within the mental health system. The fate of metro group demonstrates that those which have sought to retain

an oppositional stance find it hard to survive. It would appear that the days of independent groups campaigning to radically alter mental health services are gone and that the principles of self-organisation and grassroots activity sit uneasily with the need to fulfil contractual obligations; position users as experts on the experience of receiving mental health services, as well as experts in applying that experiential knowledge in different ways to the range of operational and strategic processes involved in running mental health services. There will, of course, always be groups who are not primarily concerned with the mental health system as such, but with wider issues such as identity, history (the Survivors History Group) or self-help movements around specific issues, such as hearing voices or self-harm. However, metro group occupied a very complex position on the 'internal/external' stakeholder dimension which we discussed in *Chapter 1* and *Chapter 3* (see *User-led organisations, Introduction*). Their membership represented constituencies defined as services (e.g. acute wards, day services) and so they were embedded in services, but at the same time their style had always been a campaigning one, prizing their autonomy and positioning themselves as external to the trust and to commissioners. And so a commissioner asked them why should she fund them to campaign against the NHS? This tension on the internal/external divide was perhaps their undoing. The group found it difficult to sustain its position as an 'external' stakeholder. All of the other groups attempted to negotiate the insider/outsider stakeholder role to the advantage of their group with varying degrees of success. Some user governors also did this in their attempts to 'represent' those who had elected them but *not* be a representative of the trust. This was the main ground for sustaining some autonomy, which most user groups and SU governors valued. But often it came at a price, such as the arts group not being able to provide the services it wanted to or the identity group having to relinquish some control to a large voluntary organisation. The chairperson of research group again embodied the tensions of being inside and outside the trust because she was both charged with embedding PPI in research (something that the trust prized itself as leading nationally) and line managed by the director of research, who had other stakeholders to consider.

One response to organisational complexity that we observed was to 'specialise' in relation to either/both the particular group of SUs or the type of activity in which they seek to engage. Others, such as the county group, which retain a broad focus for involvement and influence, experience a considerable stretching of their resources. But the existence of user groups that retain some autonomy of operation remains important regardless of the particular strategies they adopt. To that extent, there remains some evidence of a user movement comprising a diverse network of groups, albeit that the identities adopted or promoted within that movement are more diverse than in the early days of the current movement and may be offered by service providers rather than claimed by SUs.⁶⁹ In this case, not only activities, but also identities, are in the hands of purchasers and providers, so curtailing autonomy again. Interestingly, we saw no sign of the replication that Yin⁵¹ argues characterises organisations when studied as cases: each of our groups adapted quite differently to the changing organisational context.

Behavioural norms

In our work, we found that the emotional nature and content of users' experiences and contributions to involvement processes was often seen as something that needed to be managed or subdued through training: technical knowledge as a way of curbing anger. Effective involvement was equated with the capacity of SUs to behave in a similar way to professionals. This was true with the user groups and also with the user governors and it is not a new finding as we have repeatedly argued.^{87,88} Spaces for involvement have proliferated, but in practice these remain primarily spaces that are subject to behavioural rules and norms defined by the bureau-professionalism of the NHS. The more informal working groups generated by trust B to support the work of the governing body demonstrated that informality can generate what appeared to be effective working relationships within the 'meeting format' and, as a result, different behavioural norms can emerge. But these remain within the overarching formal rules of trust governance and the CEO of this trust made it clear that more emotional and oppositional contributions were not welcome at CofG meetings. On the other hand, we heard in the deliberative workshop that this process of curbing emotion can go too far and that there are some contexts, such as staff training, in which emotion is valued.

We saw in *Chapter 3* (see *User-led organisations*) that user-led groups and organisations work in a context in which other involvement initiatives are often in place in trusts and to some extent PCTs (and now CCGs). The groups we studied were often in an uneasy relation with these bodies. In trust A there is a trust-wide user involvement group and a register for payment for SUI activities. This group works closely with the PPI lead and one effect of this is to make it harder for people from groups that have not been accepted on to this to secure a place within the system to have a voice. Indeed, the identity group found it difficult to negotiate a way of speaking up on behalf of its SUs because it *refused* to be part of this system, believing the in-house group unable to represent its SUs in a way that the identity group deemed effective. No such register exists in trust C, but we can see similar attempts to control whose voice is heard in the trust's decision to invite PALS representatives to be on the implementation working groups, rather than to invite the county group. Here, we can see the effect of introducing top-down, quasi-user involvement bodies that are effectively in competition with autonomous user groups for influence. The metro group was criticised by commissioners and providers for not having the scope of the trust's PPI evidence base on the patient experience.

This links to a question of what counts as 'evidence' regarding the experience of mental health SUs. Trust A's PPI lead repeats Care Quality Commission surveys in an attempt to discover why the trust does badly on certain indicators. PALS in all the trusts seeks evidence of complaints and satisfaction in a manner that is meant to be 'objective'. Interviews with senior staff often saw them prizing this kind of evidence to the extent that such surveys were seen to be 'representative'. Many user groups, on the other hand, felt that their grassroots experience expressed in the form of stories was closer to what was really going on for SUs. This, in turn, was seen as 'anecdote' by many staff who wanted formal evidence. In the case of the metro group, this turned into an impasse, the kind of 'sticking point' mentioned in *Chapter 1*. Other groups – such as arts and research – modulated their telling of SUs' stories by positioning themselves as professionals using these stories, as would any other front-line worker. Evaluation group took the strategy of themselves conducting surveys but in a user-focused way and this impressed senior management if not operational staff.

In most contexts, then, surveys and other metrics are replacing stories and resources to carry out surveys are beyond the reach of most ULOs and so tend to be conducted by PPI leads internal to trusts and these PPI leads are not necessarily SUs themselves. There was one context in which stories were prized by all and that was user involvement in staff training. In the deliberative workshop a CEO became quite exasperated at all the talk of how SUs must learn the language of formal contexts and negotiations, saying that 'management speak' is worthless. It was agreed that individual stories were a vital part of staff training highlighting, as they did the nature of living with a mental health condition and the experience of receiving treatments and services. The survey of front-line staff indicated that at operational level this was valued too. That the SUs surveyed themselves did not see this perhaps indicates that they are not aware of the impact of their training because they are never privy to the consequences.

Another tension brings us back to the issue of 'representativeness', one that has been to the fore ever since the inception of user involvement in mental health service delivery and change. It is said that SUs involved in consultation and other interactions with managers and decision-makers are 'not representative' of ordinary users. Two quite opposing views may be taken. On the one hand, they are depicted as atypically angry about services – and, therefore, in that move we have seen repeatedly, more pathological. On the other, they may be seen as more articulate in a way that 'ordinary' users are not. Of course, if articulate people are not allowed to speak and ordinary users cannot speak because they are not articulate, there is no space at all for a SU discourse. This has been referred to as a catch-22 situation, and it is noted widely that professionals and managers are not asked to be representative of their profession. It is interesting that a user governor in trust B both described herself as articulate and well, and said she did not think she was representing anyone else.

However, there is a question related to this that is of interest. It is clear from our ethnography and from our observations of user governors that some individuals had strong leadership qualities. Those from ULOs

tended to have had a long history in the user movement and be aware of past and present activities, as well as overarching conceptual and political goals. They certainly were not representative, in the sense of typical, of most mental health SUs. But is this not true of all leaders? Interestingly, they do not rely only on their own individual experience to pursue their goals and those of their organisations but know about collectivities and have abstracted a position that they draw on strategically in their interactions with their own groups and with decision-makers.

What is evident from this and from what we said about user governors is the need for different meanings of 'representation' to be distinguished. Not only is there a need to distinguish between democratic representation – where the representatives may not share any of the characteristics of those who elect them to act in this way, from meanings that emphasise either 'statistical representation' or 'typicality'. We also need to distinguish representation of people and representation of interests. Community health councils were constituted to act as representatives of the 'public interest' in relation to the NHS. One of the critiques of CHCs was that they were not 'representative' in terms of the characteristics of their members. An enduring confusion about these differences leads to lack of clarity about the principled basis on which involvement is built.

Informal networks and 'go to' people

We have seen throughout *Chapter 3* that informal networks were often very important to the pursuit of SU goals and wishes. In cases where access to participation and involvement was established it became apparent that it was often facilitated by the involvement of the same key representatives from the trust, that there were specific individuals in each trust who championed SUI and who could be *tagged* as 'go to' people. The 'go to' people tended to be the same individuals who were mentioned by name and singled out by user group members if they had queries, complaints and worries. Such individuals tended to have an overall respect from the groups. The 'go to' people tended to express that they understood user involvement and that they '*got it*'. Our research findings were that it was typically through informal networking and by developing personal relationships with these individuals rather than negotiating formal channels of communication that meaningful participation and SUI was facilitated.

Clearly there are difficulties with regards to relying on specific individuals or 'go to' people for gaining access to meaningful participation; there are reliability issues and it is unsustainable. Key individuals can move on and leave their post, leaving a gap that SU groups had hitherto relied on. This exact issue manifested itself during the research period in one trust, when the group had developed strong links with one individual over a significant period of time. During the research period this key individual left his post in the trust. This made for a significant lack in the informal networks sustaining user involvement in this trust.

It should be clear that informal networks and 'go to' people do not exist in some space outside organisational structure. They are part of the organisation, its culture and the tacit knowledge that both SUs and mental health professionals are able to draw upon and act within.

Managing health and well-being

Finally, we have repeatedly emphasised the need not to pathologise SUs or reframe emotion as illness. But there is an issue. Mental health SUs who adopt public roles, and the decision-makers who interact with them, have a fine and complex balance to strike. Mental distress is real and a less-than-perfect experience of treatments and services is often a reason for becoming involved. Although some senior staff were of the view that it is preferable to deal with ex-SUs, most realised that currently involved users continued to have some difficulties. How then to avoid the trap of pathologising emotions as a recurrence of symptoms while at the same time appreciating that what is being asked of involved SUs constitutes a stressful environment at the least? Two of the leaders of our user groups received no payment for their work, which was entirely voluntary, and SU governors are likewise not remunerated. Working in demanding situations within limited timeframes, tight budgets and trying to attend meetings at unsuitable times all transpired as being of significant concern to SU representatives in terms of managing health and well-being while participating meaningfully. In terms of user governor involvement, it was said on occasion that senior board members

need to better understand the consequences of poor mental health, and how it can affect a person's ability to carry out their duties meaningfully. It was noted in one focus group that structures need to be in place that can take up the slack in the event of absence, no matter how short the notice or how quick the onset of illness. Again, the leader of identity group repeatedly mentioned her responsibilities as being a considerable source of stress and described how the associated fatigue impacted her mental health and general well-being. If NHS managers are unaware of the practical challenges of time constraints and limited resources that user groups are confronted with then there are likely to be problems during points of collaboration.

In the final section of this report we draw out key conclusions about the current state of SUI in mental health services and the impact this is having. We also suggest implications in terms of recommendations for managers to ensure that such involvement is not only of benefit for their organisation, but can enable SUs to experience positive outcomes from their involvement.

Chapter 5 Conclusion and recommendations

When we started this research we knew that we would be working in a climate of organisational change, although the extent of this was unforeseen. We also hypothesised that we would witness a transitional move from collective forms of user involvement to those based more on individuals. The picture we have drawn suggests something more complex, in which we need to understand SUI as contributing to change processes as well as impacted by them.

Our results lead us to draw positive conclusions about the extent to which 'ordinary' SUs consider that they are both able to be involved and to achieve some impact as a result, although we do need to express some caution about this because the picture varied across the three trusts, and those taking part in the survey can be considered to be self-selected to an extent. It may be argued that SUI is now established on the terrain of mental health in a way that was not the case in the mid to late 1990s. We may thus be seeing a 'trickle down' to participants who heretofore would not have been involved.

Nonetheless, this involvement is probably limited in two ways. First, most respondents to the survey were involved in only one or two domains, and, second, the form the involvement took did not, as far as we could gather, extend to membership of user groups or other in-depth activities. Furthermore, both SUs and professionals drew on a 'therapeutic' discourse when asked in more detail about how involvement affected SUs, a form of participation which Arnstein⁸⁹ dismisses as 'tokenism'. This, however, may not be immediately transferable to mental health as 'disruption of the self' is often part of a mental health condition and so its restoration must be seen in a positive light. In addition, both SUs and front-line staff mentioned shaping services and having a voice as consequences of user involvement and we argued that 'voice' is key in mental health in *Chapter 1*.

Thus, we suggest that there is some cause for optimism but not complacency in relation to the embedding of SUI within mental health services. The importance of voice per se should not be ignored, but both the extent and the degree of impact needs to be understood by reference to our more detailed qualitative findings – it cannot be captured solely by means of survey data.

First, we consider the issue of individual involvement compared with collective involvement. As we have noted, the expansion of means by which SUs can be involved requires us to modify the way this distinction is expressed. There is still evidence of collective involvement and it would be wrong to say that the mental health SU movement no longer exists. But because user involvement is now integrated into the conduct of trust business, and within both individual and collective service delivery practice, it has become even more important to distinguish the different ways in which user influence can be achieved, rather than draw a rather simplistic dichotomy between individual and collective influence. Individual user and user groups need to make decisions about the way in which they can most effectively focus their efforts. Managers and service providers need to understand the different ways in which the knowledge and expertise of SUs can contribute to the conduct of trust business, the delivery of services and the training of staff, and distinguish the different modes of involvement appropriate to these different purposes.

Although user-led groups and organisations have had to adapt to organisational change and to the official adoption of user involvement as 'trust business', collective organisation among SUs remains important. This is not only to offer support to involved users and to enable a wider range of experiences and views to be reflected, it is also important for mental health services that there is a focus for establishing and maintaining dialogue with an ever-expanding user population. The key issues for managers to enable this are:

1. Recognise the need for such groups to generate their own agendas and identify issues important to SUs that need action and response, rather than assume that groups will only or primarily respond to trust agendas. This also requires an acknowledgement that there are times when such groups will oppose trust policy or practice, as well as working collaboratively with providers.

2. Ensure sufficient support for such groups to enable them to (1) keep in contact with their members to ensure that they are able to reflect a wide range of user interests, and (2) prevent group leaders becoming burnt out because they are having to cover too much ground.
3. Take responsibility for ensuring that both staff attitudes and systems are designed to enable positive responses to the contributions being made by SUs. This may well mean focusing more on systems to respond to SUs than expanding the number of initiatives to involve SUs.
4. Enable effective co-ordination between SUI taking place in different contexts, in particular that there are effective links between the representational roles of user governors involved in strategic decision-making, and input from users within specific services or in the context of research, training and staff recruitment.

A key aspect of the current context concerns the shift to new forms of commissioning. Our results suggest that there is a real danger that SUs' voices will be lost as different stakeholder groups seek to establish their positions within this new system. The developments of CCGs constitute one aspect of an increasingly complex environment that is creating challenges in terms of how user groups and organisations position themselves, what kind of relationships they seek to develop and with whom. And neither commissioners nor providers appeared very clear about how they should respond in terms of how to develop ways of working with SUs in this context. The separation of commissioning from service provision and the need for commissioners to adopt a future-orientated perspective, as well as to respond to current imperatives reinforces the value of effective user groups operating outside the confines of particular service delivery organisations.

All of these issues, plus the more general and enduring issue of the complexity of the mental health system and users' places within it, imply that it is naive to assume that the introduction of personalisation can transform the power relationships between SUs and providers. The dominance of the personalisation narrative as one of progressive transformation via individual choice is behind the view (expressed by some interviewees) that consultation with current SUs will generate the 'wrong' results, including a wish to retain day centres – a model of collective service provision that is welcomed by some SUs⁹⁰ but is out of favour with those advocating personalised services. Personalisation remains a source of bewilderment to SUs, and some staff, at this stage but we witnessed both collective purchasing of a service and an attempt to use a specialised group when collective provision of a more generic kind had been withdrawn.

From the perspective of reflecting on the complex context for and impact of SUI we need also to consider different and sometimes competing service philosophies that are evident. It is not possible either to mark a clear distinction between 'progressive' and 'conservative' views of different service models, or to assume that different perspectives necessarily reside with users or providers. But in addition to the different and sometimes incompatible discourses underpinning different views about what SUI *is* and *is for* (see *Chapter 3, Managers', commissioners' and clinicians' views on user involvement*), we are seeing a more complex set of ideas about how mental health professionals should work to support those with mental health difficulties than was the case when the key debate was whether treatment should be provided in hospitals or in community settings. SUI has made an important contribution to the development of new thinking about services, but there is also evidence of professionals enthusiastically taking control of such developments (e.g. recovery) in ways that may leave little space for SUs to continue to feel able to shape directions.

Finally, it is important to note the significance of research and evaluation as a site for user involvement in mental health services. This highlights disputes over what forms of knowledge are recognised as legitimate and necessary in informing understanding of what it means to live with mental illness and how services can improve people's lives. Thus, it brings academic researchers within the scope of those who need to learn how to work differently if user involvement in research is to amount to more than tokenism.

Limitations

The survey part of the study had two limitations. First of all, respondents, particularly front-line staff, may have been self-selecting thus leading to bias. Second, our survey data represent *perceived* impact of SUI activity in a large sample. The ethnography did, however, look at impact in vivo and in practice. A further limitation was that it was impossible for researchers to attend all of the subcommittee meetings of trust governance structures, especially in trust B where these were very well developed. This means that we are missing out on potentially rich material. Finally, as with all research, but especially observational research and interviews, there may be a 'researcher effect' through which the presence of the researcher exerts some impact on the data collected. We even had one instance where a ULO attempted to use the researcher's presence to broker negotiations for funds.

Chapter 6 Recommendations for further research

Our main research recommendation is for further investigation of personalisation in the mental health field. What we found was a significant gap between the rhetoric of personalisation and the experience of both potential and actual participants in our focus groups. Our efforts to recruit to focus groups were frustrated at every turn because neither staff nor SUs knew who had personal budgets and who did not. We were told by some staff that there were people with personal budgets who were not aware that they were in receipt of them. Personalisation seems to be built on the model of support for physical impairment and is not immediately transferable to the domain of mental health. Our study was, however, small and it is possible that it is too early to tell. We therefore recommend that more detailed research with a wider sample is conducted into personalisation in mental health, both comparing with other medical and social care specialties and looking at the balance of services that are lost and gained.

Our survey of 'ordinary' users and of front-line staff is, as far as we know, the first of its kind. There were some limitations, including in the sampling frames and in interpreting the meanings that were behind the answers of participants. More concrete ways of examining impact would be helpful. We therefore recommend more research in this area.

We could find no literature on SUI in commissioning. Given the move to CCGs with stakeholder representation and a spotlight on values-based commissioning, we recommend research on the role of mental health SUs on the commissioning process.

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Contributions of authors

Diana Rose (Professor of User-Led Research, King's College London) oversaw the study as a whole and undertook data collection and analysis in trusts A and C.

Marian Barnes (Professor of Social Policy, University of Brighton) oversaw the study in trust C and led on the analysis of senior staff interviews.

Mike Crawford (Professor of Health Services Research, Imperial College London) oversaw the study in trust B and led on the survey analysis.

Edward Omeni (Researcher, King's College London) conducted empirical work in trusts A and B, and analysed both quantitative and qualitative data.

Dee MacDonald (Researcher, University of Brighton) took responsibility for data collection in trust C and was involved in qualitative analysis.

Aaron Wilson (Researcher, King's College London) contributed to the qualitative work in trust A.

All researchers were involved in compiling the report.

References

1. Great Britain. *National Health Service and Community Care Act 1990*. London: The Stationery Office; 1990.
2. Great Britain. *National Service Framework for Mental Health*. London: The Stationery Office; 1999.
3. Great Britain. *Modernising Mental Health Services Safe, Sound and Supportive* 1999. London: The Stationery Office; 1999.
4. NHS Executive. *The NHS Plan: A Plan for Investment, a Plan for Reform*. London: Department of Health; 2000.
5. Department of Health. *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*. HM Government; 2007.
6. Great Britain. *Putting People First*. London: The Stationery Office; 2009.
7. Glendinning C, Challis D, Fernandez J, Jacobs S, Jones K, Knapp M, et al. *Evaluation of the Individual Budgets Pilot Programme. Final Report*. York: Social Policy Research Unit, University of York; 2008.
8. Department of Health. *New Horizons: A Shared Vision for Mental Health*. London: HM Government; 2009.
9. Britain G, Darzi A. *High Quality Care for All: NHS Next Stage Review Final Report*. London: The Stationery Office; 2008.
10. Great Britain. *Health and Social Care Act 2012*. London: The Stationery Office; 2012.
11. Great Britain. *The Health Act: Patient and Public Involvement and Public Accountability*. London: The Stationery Office; 2011.
12. Department of Health. *Equity and Excellence: Liberating the NHS*. London: The Stationery Office; 2010.
13. Perestelo-Perez L, Gonzalez-Lorenzo M, Perez-Ramos J, Rivero-Santana A, Serrano-Aguilar P. Patient involvement and shared decision-making in mental health care. *Curr Clin Pharmacol* 2011;**6**:83–90. <http://dx.doi.org/10.2174/157488411796151192>
14. Department of Health. *No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages*. London: HM Government; 2011.
15. Department of Health. *No Health without Mental Health: Implementation Framework*. London: HM Government; 2012.
16. Baggott R, Allsop J, Jones K. *Speaking for Patients and Carers: Health Consumer Groups and the Policy Process*. Basingstoke: Palgrave Macmillan; 2005.
17. Crossley N. *Contesting Psychiatry: Social Movements in Mental Health*. London: Routledge; 2005.
18. Epstein S. Democracy, Expertise, and Aids Treatment Activism. In Kleinman DL, editors. *Science, Technology and Democracy*. Albany, NY: State University of New York Press; 2000. pp. 3–32.
19. Lindow V. A vision for the future. In Beresford P, Harding T, editors. *A Challenge to Change: Practical Experiences of Building User-Led Services*. London: National Institute for Social Work; 1993. pp. 182–91.

20. Beeforth M. What does it mean to have user participation in planning? In Leiper R, Field V, editors. *Counting for Something in Mental Health Services*. London: Avebury; 1993. pp. 89–95.
21. Barnes M, Bowl R. *Taking over the Asylum: Empowerment and Mental Health*. Basingstoke; Palgrave; 2001.
22. Bowl R. Involving Service Users in Mental Health Services: Social Services Departments and the National Health Service and Community Care Act 1990. *J Ment Health* 1996;**5**:287–304. <http://dx.doi.org/10.1080/09638239650036956>
23. Bowl R. Legislating for User Involvement in the United Kingdom: mental health services and the NHS and Community Care Act 1990. *Int J Soc Psychiatry* 1996;**42**:165–80.
24. Hatzidimitriadou E. political ideology, helping mechanisms and empowerment of mental health self help/mutual aid groups. *J Community Appl Soc* 2002;**12**:271–85. <http://dx.doi.org/10.1002/casp.681>
25. The Survivors History Group. The Survivors History Group takes a critical look at historians. In M Barnes P, Cotterell M, editors. *Critical Perspectives on User Involvement*. Bristol: Policy Press; 2012.
26. Campbell P, Rose D. Action for change in the UK: thirty years of the user/survivor movement. In Pilgrim D, Rogers A, Pescosolido B, editors. *The SAGE Handbook of Mental Health and Illness*. London: SAGE; 2011. pp. 452–71.
27. Wallcraft J, Read J, Sweeney A. *On Our Own Terms*. London: Sainsbury Centre for Mental Health; 2003.
28. Ferlie E. Organisational Studies. In Fulop N, Allen P, Clarke A, Black N, editors. *Studying the Organisation and Delivery of Health Services: Research Methods*. London: Routledge; 2001. pp. 25–39.
29. Davies HT, Nutley SM, Mannion R. Organisational culture and quality of health care. *Qual Health Care* 2000;**9**:111–19. <http://dx.doi.org/10.1136/qhc.9.2.111>
30. Barnes M. *Subversive Citizens: Power, Agency and Resistance in Public Services*. Bristol: Policy Press; 2009.
31. Rose D, Wykes T, Fleischmann P, Hogman G, Tonkiss F. *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature*. SDO 08/1201/017. London: HMSO; 2002.
32. Parkes T. *Feathers and Thorns: The Politics of Participation in Mental Health Services*. Canterbury: University of Kent; 2002.
33. Gummer T, Furney S. The Business of Listening. *Health Manage* 1998;**2**:12–13.
34. Barnes M, Newman J, Sullivan HC. *Power, Participation and Political Renewal: Case Studies in Public Participation*. Bristol: Policy Press; 2007.
35. Lowndes V, Pratchett L, Stoker G. Local political participation: the impact of rules in use. *Public Adm* 2006;**84**:539–61.
36. Harrison S, Mort M. Which champions, which people? Public and user involvement in health care as a technology of legitimation. *Soc Policy Adm* 1998;**32**:60–70. <http://dx.doi.org/10.1111/1467-9515.00086>
37. Iles V. *Developing Change Management Skills: A Resource for Health Care Professionals and Managers*. SDO 08/1301/057. London: NCCSDO; 2003.

38. Crawford MJ, Rutter D, Manley C, Weaver T, Bhui K, Fulop N, *et al.* Systematic review of involving patients in the planning and development of health care. *BMJ* 2002;**325**:1263. <http://dx.doi.org/10.1136/bmj.325.7375.1263>
39. Rose D, Fleischmann P, Schofield P. User perceptions of the outcomes of user involvement. *Int J Soc Psychiatry* 2010;**56**:389–401.
40. Pilgrim D, Waldron L. User involvement in mental health service development: how far can it go? *J Ment Health* 1998;**7**:95–104.
41. Department of Health. *Building Bridges: A Guide to Arrangements for Inter-Agency Working for the Care and Protection of Severely Mentally Ill People*. London: The Stationery Office; 1995.
42. Rose D. Partnership, co-ordination of care and the place of user involvement. *J Ment Health* 2003;**12**:59–70. <http://dx.doi.org/10.1080/09638230021000058300>
43. Gould D. *Service Users Experiences of Recovery under the 2008 Care Programme Approach*. London: Mental Health Foundation, NSUN; 2012
44. Rose D, Leese M, Oliver D, Sidhu R, Bennewith O, Priebe S, *et al.* A comparison of participant information elicited by service user and non-service user researchers. *Psychiatr Serv* 2011;**62**:210–13. <http://dx.doi.org/10.1176/appi.ps.62.2.210>
45. Gillard S, Borschmann R, Turner K, Goodrich-Purnell N, Lovell K, Chambers M. 'What Difference Does It Make?' Finding evidence of the impact of mental health service user researchers on research into the experiences of detained psychiatric patients. *Health Expect* 2010;**13**:185–94. <http://dx.doi.org/10.1111/j.1369-7625.2010.00596.x>
46. Morgan D. Paradigms lost and pragmatism regained methodological implications of combining qualitative and quantitative methods. *J Mix Methods Res* 2007;**1**:48–76. <http://dx.doi.org/10.1177/2345678906292462>
47. Tashakkori A, Teddlie C. *Handbook of Mixed Methods in Social & Behavioral Research*. London: SAGE; 2002.
48. Office for National Statistics (ONS). *Census*: London. ONS; 2001.
49. Kent H, Read J. Measuring consumer participation in mental health services: are attitudes related to professional orientation? *Int J Soc Psychiatry* 1998;**44**:295–310. <http://dx.doi.org/10.1177/002076409804400406>
50. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006;**3**:77–101.
51. Yin RK. *Case Study Research: Design and Methods*. 3rd edn. London: Sage; 2003.
52. Geertz C. Thick Description: Towards an Interpretive Theory of Culture. In Geertz C, editor. *The Interpretation of Cultures: Selected Essays*. New York, NY: Basic Books; 1973. pp. 3–30.
53. Hammersley M, Atkinson P. *Ethnography: Principles in Practice*. London: Routledge; 1989.
54. Savage J. Ethnography and health care. *BMJ* 2000;**321**:1400. <http://dx.doi.org/10.1136/bmj.321.7273.1400>
55. Forrest S, Risk I, Masters H, Brown N. Mental health service user involvement in nurse education. *J Psychiatr Ment Health Nurs* 2000;**7**:51–7. <http://dx.doi.org/10.1046/j.1365-2850.2000.00262.x>
56. Beresford P. User involvement in research and evaluation: liberation or regulation? *Soc Pol Soc* 2002;**1**:95–106. <http://dx.doi.org/10.1017/S1474746402000222>
57. Fadden G, Shooter M, Holsgrove G. Involving carers and service users in the training of psychiatrists. *Psychiatr Bull* 2005;**29**:270–4. <http://dx.doi.org/10.1192/pb.29.7.270>

58. Molyneux J, Irvine J. Service user and carer involvement in social work training: a long and winding road? *Soc Work Educa* 2004;**23**:293–308. <http://dx.doi.org/10.1080/0261547042000224047>
59. Livingston G, Cooper C. User and carer involvement in mental health training. *Adv Psychiatr Treat* 2004;**10**:85–92. <http://dx.doi.org/10.1192/apt.10.2.85>
60. Rutter D, Manley C, Weaver T, Crawford MJ, Fulop N. Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Soc Sci Med* 2006;**58**:1973–84. [http://dx.doi.org/10.1016/S0277-9536\(03\)00401-5](http://dx.doi.org/10.1016/S0277-9536(03)00401-5)
61. Milewa T. User participation in service planning: a qualitative approach to gauging the impact of managerial attitudes. *J Manag Med* 1997;**11**:238–45. <http://dx.doi.org/10.1108/02689239710177350>
62. Harrison S, Barnes M, Mort M. Praise and damnation: mental health user groups and the construction of organisational legitimacy. *Public Pol Admin* 1997;**12**:4–16. <http://dx.doi.org/10.1177/095207679701200202>
63. Barnes M. Users as citizens: collective action and the local governance of welfare. *Soc Policy Adm* 1999;**33**:73–90. <http://dx.doi.org/10.1111/1467-9515.00132>
64. Sayce L. *From Psychiatric Patient to Citizen*. London: Palgrave Macmillan; 2000.
65. Barnes M, Shardlow M. From passive recipient to active citizen: participation in mental health user groups. *J Ment Health* 1997;**6**:289–300.
66. Thomas C, Rose D. Evaluation of the Dragon Café. *Report to The SLAM Charitable Trustees*, London, 2013.
67. Rose N. governing risky individuals: the role of psychiatry in new regimes of control. *Psychiatr Psychol Law* 1998;**5**:177–95. <http://dx.doi.org/10.1080/13218719809524933>
68. Priebe S, Frottier P, Gaddini A, Kilian R, Lauber C, Martínez-Leal R, et al. Mental Health Care Institutions in nine European countries, 2002 to 2006. *Psychiatr Serv* 2008;**59**:570–3. <http://dx.doi.org/10.1176/appi.ps.59.5.570>
69. Barnes M. Survivors, consumers or exerts by experience? Assigned, chosen and contested identities in the mental health service user movement. In Jasper J, McGarry A, editors. *Social Movements and Contested Identities*: in press.
70. Simpson E, House A, Barkham M. *A Guide to Involving Users, Ex-Users and Carers in Mental Health Service Planning, Delivery or Research: A Health Technology Approach*. Leeds: Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds; 2002.
71. Monitor. *New Guidance for NHS Foundation Trust Governors*. 2009. URL: www.monitor-nhsft.gov.uk/home/news-and-events/media-centre/latest-press-releases/new-guidance-nhs-foundation-trust-governors (accessed 9 April 2013).
72. Monitor. *Your Statutory Duties: A Draft Reference Guide for NHS Foundation Trust Governors*. 2012. URL: www.monitor-nhsft.gov.uk/home/news-events-and-publications/our-publications/browse-category/guidance-foundation (accessed 9 April 2013).
73. Dixon A, Storey J, Rosete AA. Accountability of Foundation Trusts in the English NHS: views of directors and governors. *J Health Serv Res Policy* 2010;**15**:82–9. <http://dx.doi.org/10.1258/jhsrp.2009.009078>
74. Lewis R, Hinton L. Citizen and staff involvement in health service decision-making: have National Health Service Foundation Trusts in England given stakeholders a louder voice? *J Health Serv Res Policy* 2008;**13**:19–25. <http://dx.doi.org/10.1258/jhsrp.2007.007003>

75. Wright J, Dempster P, Keen J, Allen P, Hutchings A. The new governance arrangements for NHS foundation trust hospitals: reframing governors as meta regulators. *Public Admin* 2012;**90**:351–69. <http://dx.doi.org/10.1111/j.1467-9299.2011.01975.x>
76. Wilmot S. Foundation trusts and the problem of legitimacy. *Health Care Anal* 2004;**12**:157–69. <http://dx.doi.org/10.1023/B:HCAN.0000041188.79809.05>
77. Fishkin JS. *Democracy and Deliberation: New Directions for Democratic Reform*. Cambridge: Cambridge University Press; 1991.
78. Cairney P. *Understanding Public Policy: Theories and Issues*. London: Palgrave Macmillan; 2012.
79. Barnes M, Newman J, Knops A, Sullivan H. Constituting ‘the public’ in public participation. *Public Adm* 2003;**81**:379–99. <http://dx.doi.org/10.1111/1467-9299.00352>
80. Young IM. *Inclusion and Democracy*. Oxford: Oxford University Press; 2002.
81. Haynes P. Chaos, Complexity and Transformations in Social Care Policy in England. *Publ Money Manag* 2007;**27**:199–206. <http://dx.doi.org/10.1111/j.1467-9302.2007.00580.x>
82. Needham C. Personalisation: from day centres to community hubs? *Crit Soc Pol* 2014;**34**:90–108.
83. Barnes M, Gell C. The Nottingham Advocacy Group: a short history. In Barnes M, Cotterell P, editors. *Critical Perspectives on User Involvement*. Bristol: The Policy Press; 2012.
84. Cornwall A, Coelho VS. *Spaces for Change? The Politics of Citizen Participation in New Democratic Arenas*. London: Zed Books; 2007.
85. Barnes M. Is the Personal No Longer Political? A response to Charles Leadbeater, Jamie Bartlett and Niamh Gallagher’s Making It Personal (Demos, 2008). *Soundings* 2008;**39**:152–9.
86. Lipsky M. *Street-level Bureaucracy: Dilemmas of the Individual in Public Services*. New York, NY: Russell Sage Foundation; 1980.
87. Church K. Beyond ‘bad manners’: the power relations of ‘consumer participation’ in Ontario’s Community Mental Health System. *Can J Commun Ment Health* 1996;**15**:27–44.
88. Barnes M. Passionate participation. *Crit Soc Pol* 2008;**27**:461–81.
89. Arnstein SR. A Ladder of citizen participation. *J Am Inst Plann* 1969;**35**:216–24. <http://dx.doi.org/10.1080/01944366908977225>
90. Barnes M, Davis A, Rogers H. Women’s voices, women’s choices: experiences and creativity in consulting women users of mental health services. *J Men Health* 2006;**15**:329–41.

Appendix 1 Coding frame for senior staff interviews

1. *How are SUs in general talked about? As patients; citizens; needy individuals; people with the potential to grow/develop/recover; by reference to diagnosis/condition and its severity; others?*
2. What is user involvement – what discourses are employed to construct what SUI means?
 - Empowerment/rights.
 - Stakeholder.
 - Consumer.
 - Responsible citizen.
 - Expert by experience.
 - Therapeutic.
 - Educational.
 - Collective action.
 - Individual involvement.
3. What mechanisms for involvement are identified?
 - Consultation (face to face).
 - Feedback (questionnaires, etc.).
 - Shared decision-making – individual.
 - Personal budgets as a means to exercise individual choice.
 - Advocacy.
 - User councils in specific services.
 - Membership of governance boards.
 - Recruitment of staff.
 - Training.
 - Research.
 - Peer mentoring/support/training.
 - Others.
4. *How do interviewees describe their own roles/position and that of others vis-à-vis involvement?*
 - Committed advocate/supporter.
 - Interested.
 - It's someone else's job.
 - Another responsibility for which they do not have time.
 - Unconvinced.
 - Uncertain about their skills in this.
 - Oppositional.
 - Others.
5. *Impact of involvement – are impacts being identified in the following arenas?*
 - Clinician/user relationships and interactions.
 - Service design and delivery.
 - Recruitment decisions.
 - On SUs themselves: self-esteem, recovery, etc.
 - On opportunities for social interactions among SUs.

- On clinicians'/managers' understandings of what living with mental illness and using services means (general/others in the trust).
 - On the interviewee personally: values, attitudes, ways of working.
 - On ways of doing things – including decision-making processes.
 - Others.
6. How does/does user involvement shape institutional rules and norms?
- Any examples cited of changes in procedural rules?
 - Any examples cited of changes in behavioural rules/norms?
 - Any personal reflections on 'cultural shift'?
 - Evidence of any changes in the way in which user involvement is being seen and happening over time.
7. *How do institutional rules and norms shape involvement practices?*
- How are institutional rules described/explained?
 - How are behavioural rules described/explained?
 - What assumptions are being made about constraints/opportunities of external context on user involvement (e.g. national policy)?
 - What assumptions are being made about constraints/opportunities of local context on SUI (e.g. locally determined procedures)?
 - What 'rules of the game' are evident?
 - Any specific reference to the impact of performance indicators?
 - Any specific reference to the impact of the development of markets in health and social care?
 - How does the level at which involvement happens shape practices?
8. *Knowledge/expertise:*
- References to specific types of knowledge: professional; bureaucratic/procedural; research; lay; experiential.
 - Judgements of legitimacy/validity of forms of knowledge.
 - Identifications of skills/capacity specific to forms of involvement/participation.
9. *Constructing 'SUs' – How are SUs who become involved in user involvement initiatives described?*
- Knowledgeable.
 - Committed.
 - Experienced.
 - Professional.
 - Political.
 - Angry.
 - Emotional.
 - Mad, irrational.
 - Unrepresentative.
 - Self-interested.
 - 'Professional users'.
 - 'Usual suspects'.
 - Inexperienced.
 - Lack understanding.
 - Needing support/training.
 - Others?

A decorative graphic consisting of numerous thin, parallel green lines that curve from the left side of the page towards the right, creating a sense of movement and depth.

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