

User Involvement in Mental Health Settings

Experiences of User Involvement in Mental Health Settings: User Motivations and Benefits

Accessible Summary

What is known on the subject:

- User involvement, when people who have accessed services become actively involved in aspects of mental health care, can sometimes be 'tokenistic' and not well thought through.
- Users are often involved in their own care, and asked for feedback, but are less likely to be meaningfully involved in developing services and training staff.

What this paper adds to existing knowledge:

- To implement meaningful involvement, it is important to know why some users choose to devote time to such activities.
- User representatives in this study, involved in a UK mental health service, wanted to help people in a similar position and give something back to those that helped them. As people started involvement activities, such as interviewing staff, they gained confidence and felt part of something that was making a difference. After being supported by staff

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to explore opportunities, representatives become more independent and some moved to different, sometimes salaried, roles. Some representatives did not feel valued or supported. Staff often controlled opportunities, and many users missed out on being involved.

What are the implications for practice:

- Staff need to understand and receive training on involvement. The definition of involvement should be agreed by users and staff together, and outcomes of involvement activities must be fed-back to users on a regular basis.
- There should be dedicated involvement workers in services, to support individuals and integrate involvement into the system. It is important to consider how to make involvement accessible for more mental health service users.

Abstract

Introduction: Despite guidance promoting user involvement, meaningful involvement continues to be debated within services. To effectively implement involvement, it is important to acknowledge why users devote time to such activities.

Aim: This study explores user representatives' experiences of involvement, including motivations and personal benefits.

Method: Thirteen user representatives involved in activities such as staff training and interviews were recruited from a UK National Health Service mental health Trust during 2015. Themes within semi-structured interviews were developed using constructivist grounded theory analysis. Memo-writing, process and focused coding, and core categories supported development of the conceptual framework of being a user representative.

Findings: Being a user representative was inextricably linked to wellness, yet staff governed opportunities. Making a difference to others and giving back were initial motivating factors. Experiences depended on feeling valued, and the theme of transition captured shifts in identity.

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Discussion: User representatives reported increased confidence and wellbeing when supported by staff. However, involvement triggered mental health difficulties, and identified need for regular monitoring and reflection of involvement activities and practice.

Implications for practice: Services should consider coproduction, where users and staff agree together on involvement definitions. Dedicated involvement workers are crucial to supporting individual wellbeing and monitoring involvement.

Relevance Statement

UK and international guidance places emphasis on user involvement in mental health settings. Yet research calls for further enquiry into the impact of involvement upon wellbeing and recovery. It is key for mental health professionals to understand motivations and benefits to effectively facilitate involvement opportunities. This paper explores user involvement processes, providing suggestions for mental health services to develop meaningful involvement, and challenges to be aware of.

Key Words:

Organisational Change/Development

Patient Experience

Qualitative Methodology

Service Evaluation

User Involvement

Introduction

User involvement describes the process whereby individuals become actively involved in aspects of health care, rather than passive recipients of such services. First observed from a psychological perspective in Arnstein's (1969) Ladder of Participation, full involvement requires re-evaluation of historically hierarchical relationships, in the absence of which participation can be regarded as tokenistic.

User involvement in adult mental health services spans the entire participation ladder, including involvement in one's own care (Storm & Davidson, 2010; Tambuyzer & Van Chantal, 2013), service evaluation (Malins et al., 2011), service development (Haigh et al., 2007; Restall & Strutt, 2008), peer support (Pitt et al., 2013), staff training (Chambers & Hickey, 2012), guidance development (Haigh et al., 2007; Harding et al., 2011), and research (Kara, 2013). Debates exist around the effectiveness of user involvement, with barriers including unresolved power differentials, resultant tokenism and lack of tangible change (Restall & Strutt, 2008; McDaid, 2009; Rose et al., 2010).

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A call for mental health services in the UK to provide more influence and choice for users has emerged over recent years (Department of Health (DoH), 2011; Her Majesty's Stationery Office (HMSO), 2010). The National Institute for Mental Health England's involvement framework (Health and Social Care Advisory Service (HASCAS), 2005) recommends involvement structures become embedded within services. There is recognition that the National Health Service (NHS) must become more responsive to user needs and wishes (HMSO, 2006; 2007) and include users in the development and monitoring of services (Pearson, 2006). Developing users' knowledge, skills, confidence, and leadership, and embedding user involvement within organisations to determine formal links to human resources, finance, and governance (HASCAS, 2005; National Survivor User Network, 2014) are seen as means to redress user influence and provide effective systems of engagement (Schehrer & Sexton, 2010).

The World Health Organisation (2010) asserts the importance of users in mental health services adopting self-determination. They suggest the need for user influence on social and political strategy, with involvement in decision-making and organisational development. The

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UK National Institute for Health and Care Excellence (NICE) developed clinical guidance reaffirming this message; *Service User Experience in Adult Mental Health* (2011). NICE state that feedback from mental health users should be used to monitor and improve services, and users should be involved in the planning and delivery of mental health training. *No Health Without Mental Health* (DoH, 2011) suggests greater emphasis on user involvement in determining priorities, planning local services, and developing anti-stigma activities. These may contribute to an individual's recovery (gaining a sense of agency, opportunity and hope), addressing discrimination and power differentials (Centre for Mental Health, 2017). Investigations into major failings within UK health services resulted in the *Transforming Care* report (DoH, 2012), which stated health and social care commissioners should be accountable to users, and demonstrate how users have been involved in their own care and the planning and commissioning of services. *The Mid Staffordshire NHS Foundation Trust Public Enquiry Report* (Francis, 2013) proposed that users inspect care providers, to prevent poor practices, and put systematic checks in place to hear and respond to user experiences.

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Adult mental health services need to develop ways to adopt these requirements, whilst engaging users in a meaningful involvement process. Coproduction, the notion of using reciprocity to develop relationships between professionals and users to plan and develop support together, has been identified as a means to improve social inclusion, address stigma, improve skills, and aid prevention and wellbeing (Slay & Stephens, 2013).

The most recent strategic documents regarding NHS England's *Five Year Forward View* (2016; 2017) set out priorities for genuinely involving 'patients and communities' to progress predetermined key priorities and address challenges. The documents do not mention coproduction, however recommend users are involved from the start in coming up with potential solutions, have time to consider plans and feedback, and that NHS Trusts report back to users how feedback has been used (NHS England, 2017).

A narrative review of literature between 2004-2014 identified existing knowledge from empirical studies regarding user involvement in service development (Neech, 2015). International studies ranged from service evaluation and planning of services and consumer groups

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in Canada (Restall & Strutt, 2008), assessing and evaluating involvement development plans in community mental health hospitals in Norway (Storm et al, 2011; Rise et al, 2013), exploring clinician and user perceptions of participation in rural Australia (Kidd et al, 2007), and perceived impact of involvement in day centres, evidence of user involvement influence, factors influencing involvement implementation, and user group members 'representativeness' within statutory UK mental health services (Rose et al 2010; Horrocks et al 2010; Rutter et al 2004; Crawford & Rutter 2004). The review identified two studies in the voluntary sector; exploring the use of the equality of condition framework to view involvement in advisory committees in Ireland (McDaid, 2009), and comparing the process and outcomes of two approaches to engaging mental health users in quality assurance processes in a UK day centre for minority ethnic groups (Weinstein, 2006).

The review highlighted that despite international calls for additional emphasis on user involvement to improve services, a number of barriers prevented meaningful involvement. To avoid tokenism, power differentials needed addressing, and users needed to see tangible change as a result of their involvement activities. No

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identified studies explored users' motivations for taking on an involvement role within an organisation, yet this seems key to understanding criteria for successful involvement and engagement in participation activities.

There is evidence that involvement has positive effects for individuals (Petersen et al., 2008), and can prevent feelings of helplessness (Greenall, 2006), yet no papers have been identified that explore the initial personal motivations for individuals and the subsequent impact upon wellness and recovery as they move through their involvement journey.

Despite governmental and policy drivers, meaningful user involvement remains an area for development. Some UK studies have found professionals within organisations hold differing views towards involvement, for example those practising within a medical model can find involvement disempowering, challenging the assumption of staff as 'experts' (Soffe et al., 2004). Bertram and Stickley (2005) highlighted defensive practice, paternalistic attitudes and stagnant views embedded in the culture of mental health services as barriers for involvement. Criteria for successful involvement also varies within organisations; more frequent involvement does not necessarily imply genuine

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involvement, even when quantitative outcomes (e.g. numbers of users involved in service development) are met (Rise et al., 2013).

Rationale

To understand how user involvement and representation in mental health settings can be most effectively implemented, it is important to acknowledge why some users choose to devote their time to such activities.

People with mental health difficulties, who have opted to become user representatives, offer knowledge and experience that is vital to understanding definitions of meaningful involvement, motivations to become involved, and personal or organisational outcomes of successful involvement. Developing our understanding of the user perspective could enhance understanding of involvement amongst staff and users, normalising meaningful involvement within services.

Aims and Objectives

This study is the first to explore user representatives' experiences of involvement within mental health services, focusing on their initial motivation, perceived opportunities in relation to getting involved, and perceived outcomes of involvement.

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Research Questions

The principal research question asked how do mental health user representatives experience user involvement? To fully understand this, the study aimed to answer the following questions: Why do individuals become user representatives? What outcomes are achieved in the role of user representative?

Method

Methodological Approach

Grounded theory seeks to discover basic social and psychological processes without forcing data into pre-conceived categories (Charmaz, 2013). Constructivist grounded theory (Charmaz, 2013) was deemed a suitable approach, as the study aimed to explore the interpretation and meaning of current practice and activities as related to user involvement, from the perspective of user representatives, but viewed through the lens of a co-constructed interpretation via the researcher-participant interaction, to develop a theory and conceptual framework.

Reflexivity and Rigour

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The primary researcher was a female trainee clinical psychologist with placements in adult mental health settings, conducting doctoral research in a neighbouring NHS Trust. The primary researcher had previous experience and interest of user involvement, and had received research methods and governance training. The research team included two user representatives who had received services within the Trust in which the research was conducted. The primary researcher had no prior relationship with participants, and had met user representatives on the research team during clinical training activities where they were involved in recruitment and training of staff, and where they had indicated an interest in being involved in research activities.

The study questions, aims and design were coproduced with the user representatives in the research team, and together grounded theory training, recruitment, coding and analysis was undertaken. User representatives on the research team were consulted at each step of the analytic process and given small non-identifiable excerpts to code. This supported the team to ensure that emerging interpretations were grounded in the data.

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Recruitment

Participants were recruited from a large NHS mental health Trust in the West Midlands region of England. Recruitment took place during an annual user and carer celebration day, and via existing involvement networks within the organisation. The primary researcher spoke at two user forums to introduce and explain the study in more detail, and distributed information sheets. Staff responsible for user involvement within the Trust promoted the study to all registered user representatives. In addition to convenience sampling, snowball sampling was employed to identify other potential participants.

Participants

The thirteen participants interviewed in the study (Table 1) self-identified as being current or past users of adult mental health services, and current or past user representatives within the organisation (a role defined by the Trust, requiring training). Participants had participated in at least one involvement activity, including peer support, research, consultation, staff interviews, training, or attendance at forums and committee meetings. Five participants had experience working in salaried user involvement roles in the Trust and voluntary sector organisations. All participants were entitled to sessional

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fees for involvement activities in line with the Trust's involvement policy.

(Insert Table 1 here)

Ethics and Risk

The study was reviewed and given favourable opinion by a NHS Research Ethics Committee (reference number 14/EM/0159) and University Independent Peer Review panel. Ethical considerations included the acknowledgement that some individuals might find it difficult to speak about previous experiences of mental health services. Information regarding further support was available to participants, including contact details and the Patient Advice and Liaison Service. Disclosure of risk was considered, and confidentiality within the confines of safeguarding was explained to participants. Informed consent was required to take part in the study, gained on the day of the interview, after the research was explained and participants had been through an information sheet with the researcher. Participants were told they could stop at any time, could withdraw their participation without giving a reason, and were given a support sheet upon completing their interview.

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Procedure

Participants took part in face-to-face semi-structured interviews with the primary researcher, lasting 38-76 minutes, with six choosing to be interviewed in their own home and seven on Trust premises. The interview guide was developed by the researcher and user representative members of the research team. The guide included the following topic areas: reasons for starting the role, personal outcomes and achievements, and positive and negative elements of the role.

Analysis

Initial line-by-line coding of interview transcripts generated active statements to describe processes as they related to user representation. A list of focused codes was produced by grouping initial codes into common themes, then comparing them with the data using constant comparison (Tweed & Priest, 2015).

Memo-writing assisted with analysis of focused codes, and connections between participant experiences and processes occurring within the role of user representative were captured. In line with the iterative analytical process of grounded theory, the interview guides were adjusted to explore emerging themes and recruitment progressed,

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where possible, via theoretical sampling. Memos were reconstructed several times, and connections made between focused codes before final categories and a conceptual framework were reached. Interviews ceased once a level of saturation of categories was reached, and participants confirmed the final conceptual categories, which were considered to best represent the data.

Findings

The constructivist grounded theory process resulted in development of a conceptual framework (Figure 1). The framework connects the overarching themes of *staff governing involvement* and user representatives' feelings of *wellness*. The initial motivating factors of users wanting to contribute to *future user experiences* and *giving back* are depicted, along with the maintaining and modifying factors of experiencing *transitions* and *feeling valued*. The arrows signify the transitions individuals make between different stages of being a user representative.

(Insert Figure 1 here)

Overarching Themes

Staff Governing Involvement

Staff members' power over user involvement was apparent, with all participants acknowledging that certain individual professionals raised awareness and recruited for involvement activities. Users relied on communication from their clinician for information regarding involvement, and in most cases there were no other sources of information. Involvement was initially opportunistic, leading to further involvement activities.

It's kind of pot luck if there's a professional that knows about it, and knows you. (Participant 7)

I just took a chance and emailed [clinician with strategic responsibilities], said... 'if I can help out in any way, then let me know'. And it kind of just started to evolve from there...getting a service user involvement fee, it wasn't an official role to start with. (Participant 3)

Participants acknowledged that articulate and educated user representatives were asked by staff to do more activities. Individual users were specifically asked to take part in certain activities and roles, with interview procedures to become a user representative and equality

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of opportunity being considered afterwards. One participant recalled being asked to take on a specific involvement role by a senior staff member:

This guy said 'we'd like you to be involved...to be part of this, but obviously you need to interview'.

(Participant 5)

When people know that you've used services...they either expect nothing from you, or when you can string a sentence together, everything from you.

(Participant 3)

Participants acknowledged that certain staff members had more of an interest in involving users than others. One participant spoke about no longer having staff representation at a user group, impacting the influence of the group, with no staff member to take actions further.

[The professional] could no longer attend the group...and nobody's to replace her. (Participant 6)

At times lack of staff understanding regarding involvement was clear to users.

I don't see the point in...[user] representation here, because [staff] didn't know what it was about.

(Participant 4)

Wellness

The mental health and wellbeing of user representatives was as a motivating, maintaining, and modifying factor. All participants acknowledged the role user involvement played in their recovery journey, where representatives began to experience increased confidence and engagement in meaningful activity.

I was looking for something that would build my confidence, which had been severely dented, and self-esteem. And it's certainly done that.

(Participant 11)

I was finding that intellectually, as my mind was reawakening...I found it amazingly positive for me. I'd got something to go and do in the day.

(Participant 9)

Participants experienced a sense of belonging and value through involvement activities, contributing to their recovery.

I think it was the fact that you were with like-minded people. You felt safe. (Participant 5)

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It's just given me that self-worth and value that I have something worth saying...I can't think of anything else that would have given me that so powerfully. (Participant 8)

Wellness appeared to be situated along a continuum, where users' mental health could also suffer as a result of involvement, especially with exposure to short timescales and anxiety-provoking situations. One participant recalled how they felt in the days after sitting on a staff recruitment panel:

That [scenario question in the interview] was one of my trigger points, and it caused [an] anxiety attack...I was quite poorly for a couple of weeks...churning over and over in my mind what I'd said and what I'd done. (Participant 6)

For some, there was a need to incorporate the tiring effects of involvement into their lives.

I have to remember that afterwards, the next couple of days, I'm gonna need extra sleep...look after myself after that. And I do wonder whether the people that organise it are aware that it's not just that day I'm giving. (Participant 8)

Initial Motivating Factors

Future User Experiences

Participants acknowledged their own role in the recovery of other users and in service development. It was important for them to bear witness to changes in which they played a part. There appeared to be a collective desire to change user experience for the better, by instilling hope, representing those without a voice, and making meaning from personal experiences.

*If I can do anything for anyone, to make them feel,
if nothing else, proud of what they've gone through.*

(Participant 5)

The desire to have an impact for future users was often rooted in personal experience of service failings.

*I'm not just complaining, I want things to change,
and I know it won't happen immediately...I'm doing
it more for people in the future. (Participant 7)*

Some started involvement activities recalling what it was like when they were unwell, modelling optimism and recovery for other users.

*It gives them hope...I almost got to the point where
I felt like people like us never got better.*

(Participant 2)

Giving Back

For some participants, involvement was a clear way of showing gratitude to the service that helped them.

You think 'ok, I've been a service user. Now's the time to put something back in.' Stop being just the recipient...you've received, but now you can give back. (Participant 13)

For some the initial motivator was to make amends for the difficulties they perceived causing others during their engagement with services.

I was like a massive pain in treatment, and I felt really guilty...and then thought 'oh I'd better give something back'. It was kind of like my 'I'm sorry'. (Participant 3)

For other participants there was symbolic communication, showing staff they were moving forward.

When I go back on the ward they can see me well. Which gives me a sole purpose for going back. (Participant 10)

Maintaining/Modifying Factors

Transitions

Participants described movement away from being a 'user', towards a different identity. For some this meant being able to consider and incorporate others' perspectives into their understanding of mental health difficulties.

I never thought about [carers] who've got to look after these people at home...How do these people stay well themselves, with all that they've got?

(Participant 12)

For some there was a conscious attempt to take on a new identity, focussing on a care-giving role.

I like to have the identity of somebody that helps others, rather than someone that's always taking help. (Participant 2)

You realise that you're not just a service user. And that I can actually have a profession out of this, which is what I want. Without the label service user...That's why I'm doing my degree. (Participant 8)

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Participants spoke about starting to lead a 'normal' life as a result of involvement activities, where they could relate to others within society.

For me, I felt, 'I'm paying tax again, I'm actually paying taxes and making a contribution back to society'. (Participant 12)

Many participants had aspirations to become mental health professionals, seeing involvement as a way to gain experience, make contacts, and find out what working in the service was like. Some participants had discouraging experiences in other workplaces, and believed working in mental health would reduce exposure to stigma associated with a psychiatric diagnosis.

I always thought, 'well I'm covered in scars, I can't work in the mental health profession'. But the fact that they're all treating me equal, makes me see that I can...purely doing service user involvement has spurred me on to apply for three jobs.

(Participant 8)

For some user representatives, when a paid professional role was obtained, conflict existed over the dual identity of user and staff member.

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I really struggle with where I sit, where I feel comfortable...I kind of flip between different roles...a professional or a service user, and I'm both. (Participant 3)

Involvement activities sometimes reminded users of their life prior to accessing services, yet there was a realisation that their mental health would suffer if they participated in involvement activities on a daily basis. After a day of interviews, one user representative felt torn between acknowledging the impact participation had on wellbeing, and wanting to get involved in the team's activities.

Part of you's thinking... 'that's a lesson to you, you know, that you can't actually cope in that environment anymore'. And the other part is going 'I wonder what's going on now.' (Participant 13)

Participants spoke about gaining new insight, an insider perspective, into mental health services, enabling user representatives to see services from the unique position of the user and organisation. One participant saw involvement as an opportunity to:

Do more networking, meet more people from the Trust, get my name around...you go to meetings, and you're hearing things and you're getting all the

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latest information about what their plans are, what the strategies are. (Participant 1)

Some participants appeared to value lived experience over skills and clinical ability, considering what would be different if users became staff members.

When the phone rings, they will identify with the person on the other end of the phone...and instead of saying 'look, my diary says I can get to you on Friday,' they might think 'this ain't good'. And I know that's perhaps an emotional response, rather than a clinician's response. But...why isn't that valid as well? (Participant 13)

The professionals do an amazing job. But who has better insight than people who've got lived experience? (Participant 8)

Feeling Valued

Experiencing feelings of value was important to all participants, and often made the difference between meaningful and tokenistic involvement. Most participants expressed a strong sense of feeling valued from user involvement, and to some the fact involvement existed was symbolic of the value of lived experience. Value

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came from within, from staff, other users, and fellow representatives.

I was thinking wow...people have faith in me, and they're gonna let me go and talk in front of all these people. (Participant 2)

Payment for involvement activities was frequently mentioned in relation to value, where although participants held differing beliefs regarding the importance of this, being paid was seen as validating user input into services.

I get paid...that definitely shows you're being valued, because the NHS don't really wanna give out their money. (Participant 3)

There was a general sense of dissatisfaction that representatives were rarely informed of involvement outcomes. In cases where they felt their views had not been listened to, users were less likely to feel valued, perceiving their contributions as meaningless.

There wasn't an infrastructure to enable [user representative feedback of concerns] to happen. So it was a tokenistic gesture...as far as I was concerned. (Participant 4)

Discussion

Despite the egalitarian principles underpinning user involvement, a power differential still exists within mental health practice. This study found that staff were governing involvement opportunities. As a result, user representation was based on staff-service user relationships, staff motivation, and opportunism, rather than being strategic or skills-based. Staff charged with enhancing involvement may invite users deemed to have 'professionally acceptable' qualities to act as representatives, muting the full range of experience from those within services. The findings from this study suggest articulate user representatives with higher levels of education are offered more opportunities. If staff continue to act as the gatekeepers for involvement activities, involvement will not be democratic, and some users will remain marginalised. In the absence of formal, skills-based selection for specified activities, the outcomes for involvement will be minimal and representation will remain marginal.

This study highlighted the importance of identity within recovery, with meaningful user involvement having the potential to support people to challenge whether their user identity is/should be their dominant identity. Involvement

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activities can encourage people to identify with normalising and socially acceptable roles (e.g. staff member). The desire to help represents a major driver in relation to the initiation of involvement and could inform an identity shift, from care-receiving to care-giving.

Individuals want to make a difference in the lives of others, and a simultaneous process of meaning-making occurs where user representatives reflect on the value and benefit their experience has for other individuals.

This study suggests that involvement can have a positive impact, increasing confidence and opening up opportunities for meaningful social activities. However, activities should be person-centred and carefully negotiated, with support provided as required, to prevent negative impact on wellbeing. As participants highlighted, involvement can have detrimental effects upon recovery and wellbeing, particularly when activities are arranged last-minute or are not coproduced between staff and users. For example, not knowing the upcoming questions being asked on a staff interview panel, or being unaware of the size of audience or themes likely to come up from panel discussions, were all sources of anxiety. Every user representative is unique, and their different experiences and stage of recovery will determine involvement-

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associated needs. In order to fully support individuals to engage in involvement, activities need careful planning and consideration between staff and users within a service, and representatives need ongoing support, with opportunities to reflect and feedback between involvement activities, and a chance to consider personal development. Involvement should be taken at an individual pace, with attention paid to eliciting clear expectations. The question remains in relation to whether user representatives are truly representative of those using services (Crawford & Rutter, 2004), as the very nature of the role assumes users are well enough, and able to think about the experiences of others, in order to fulfil their duties.

Involvement activities will only be maintained if people derive value from them, including a sense of being valued by the service. The impact of involvement activities should be tangible, a finding from this and previous studies, where meaningful change (Rose et al., 2010) and feeling connected to decisions and outcomes (Restall & Strutt, 2008) is seen as crucial. In previous research where users were involved in meaningful involvement processes, they experienced increased confidence and self-esteem (Weinstein, 2006). In this study, when user

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representatives felt valued they reported increased confidence, wanted to develop their roles, and perceived themselves to be advancing their recovery. Over time, representatives are increasingly regarded by themselves and others as staff members and, at this point, are more likely to be treated with equity; getting their voices heard, having influence and promoting change.

During periods of mental distress, user representatives in this study described positioning themselves as different from staff, as part of a hierarchical system within the organisation and wider society. Socially constructed hierarchies impact negatively on psychological health and wellbeing (Wilkinson & Pickett, 2010). In this study, as meaningful involvement activities commenced, the 'us and them' gap narrowed, redistributing power, and moving involvement towards a more egalitarian, partnership model as envisaged by Arnstein (1969).

Limitations

The user representatives interviewed in this study may not be representative of all user representatives, but rather educated individuals with access to services and an interest in research participation. They were confident and well enough to participate in research and

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involvement activities. The study reports experiences of user representatives from one organisation.

Representatives no longer involved with the Trust were not represented, as participants were primarily recruited via existing user involvement networks. This research did not explore the experiences of carers, or users engaged in involvement activities outside of the formal representative role or within independent user groups. The findings may not be generalisable to other populations such as children, young people, and individuals with a learning disability.

Future Research

To explore the links between user involvement and wellbeing, further research that draws on user representatives from a range of different healthcare organisations is recommended, to test out the validity of the conceptual framework (Figure 1) amongst different user groups. The dynamics between staff and user representatives require further exploration to understand existing power relations, and develop possible training for staff. Another important area for inquiry is the motivation and impact of carer representation and involvement, which is likely to represent different priorities and needs (Rose et al., 2004; Cleary et al., 2006).

Implications for Practice

User involvement and representation is a growing international movement within mental health services, supporting positive service developments, opportunities for user feedback, and promoting ethical and egalitarian approaches to care.

This study suggests that despite the presence of some hierarchical power relations with staff, user involvement can meet individual needs if user representatives perceive themselves to be valued, witness tangible change, and feel able to integrate involvement activities into their recovery more broadly. In the presence of supportive environments, user representatives become increasingly able to incorporate others' perspectives into their understanding of mental health difficulties and within the presence of altruistic motivations, develop hopes for a different future for themselves, assimilating new aspects of care-giving into their identity.

A recommendation from this study is that staff education regarding coproduction and involvement would enhance knowledge and awareness. Ideally, users and staff would work together to coproduce a definition and understanding of involvement within their organisation and start their

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involvement journey together. An involvement policy (including guidance regarding payment) would help clarify uncertainty among staff. A dedicated participation/involvement worker, or peer support from experienced representatives, would support individuals to explore their involvement journey. By anticipating possible triggers and difficulties, and putting together wellbeing plans for involvement, with regular reviews, involvement should be more rewarding and effective for both individuals and services.

Regular updates from mental health services regarding the impact of involvement is key to communication and highlighting the impact and value of such activities; this could be in the form of an involvement newsletter, email update, conference, or celebration day.

Organisations that foster a culture of open communication regarding the benefits of involvement, and its impact on services and individual users are critical, as user involvement becomes increasingly valued within mental health services.

References

- Arnstein, S.R. (1969). A ladder of citizen participation.
Journal of the American Institute of Planners, 35(4),
216-224. doi: 10.1080/01944366908977225
- Bertram, G. & Stickley, T. (2005). Mental health nurses,
promoters of inclusion or perpetrators of
exclusion? *Journal of Psychiatric & Mental Health
Nursing*, 12(4), 387-396. doi: 10.1111/j.1365-
2850.2005.00849.x
- Centre for Mental Health (2017). *What is Recovery?*
Retrieved from
<https://www.centreformentalhealth.org.uk/recovery>
- Chambers, M. & Hickey, G. (2012). *Service User
Involvement in the Design and Delivery
of Education and Training Programmes Leading to
Registration with the Health Professions Council*.
London: Kingston University and St George's,
University of London.
- Charmaz, K. *Constructing Grounded Theory*. (2013). 2nd
ed. London: Sage.
- Cleary, M., Freeman, A. & Walter, G. (2006). Carer
participation in mental health service delivery.

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International Journal of Mental Health Nursing,

15(3), 189-194. doi: 10.1111/j.1447-

0349.2006.00422.x

Crawford, M.J. & Rutter, D. (2004). Are the views of members of mental health user groups representative of those of 'ordinary' patients? A cross-sectional survey of service users and providers. *Journal of Mental Health, 13*(6), 561-569. doi: 10.1080/09638230400017111

Department of Health (2011). *No Health Without Mental Health*. London: DoH.

Department of Health (2012). *Transforming Care: A National Response to Winterbourne View Hospital: Department of Health Review Final Report*. London: DoH.

Francis, R. (2013). *Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry*. London: The Stationary Office.

Greenall, P. (2006). The barriers to patient-driven treatment in mental health: why patients may choose to follow their own path. *International Journal of Health Care Quality Assurance, 19*(1), xi-xxv. doi: 10.1108/13660750610643822

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- Haigh, R., Lovell, K., Lyon, F. & Duggan, M. (2007). Service user involvement in the National PD Development Programme. *Mental Health Review*, 12(4), 13-22. doi: 10.1108/13619322200700034
- Harding, E., Pettinari, C.J., Brown, D., Hayward, M. & Taylor, C. (2011). Service user involvement in clinical guideline development and implementation: learning from mental health service users in the UK. *International Review of Psychiatry*, 23(4), 352-357. doi: 10.3109/09540261.2011.606802
- Health and Social Care Advisory Service (2005). *Making a Real Difference: Strengthening Service User and Carer Involvement in NIMHE: Final Report*. London: HASCAS.
- Her Majesty's Stationery Office (2006). *The National Health Service Act 2006. Chapter 41*. London: HMSO.
- Her Majesty's Stationery Office (2007). *The Local Government and Public Involvement in Health Act 2007 (Commencement No. 1 and Savings) Order 2007, Chapter 125, Article 2(a)*. London: HMSO.
- Her Majesty's Stationery Office (2010). *Equity and Excellence: Liberating the NHS*. London: HMSO.

User Involvement in Mental Health Settings

- Horrocks, J., Lyons, C., Hopley, P. (2010). Does strategic involvement of mental health service users and carers in the planning, design and commissioning of mental health services lead to better outcomes? *International Journal of Consumer Studies*; 34, 562-569. doi: doi:10.1111/j.1470-6431.2010.00912.x
- Kara, H. (2013). Mental health service user involvement in research: where have we come from, where are we going? *Journal of Public Mental Health*, 12(3), 122-135. doi: 10.1108/jpmh-01-2013-0001
- Kidd, S., Kenny, A. & Endacott, R. (2007). Consumer advocate and clinician perceptions of consumer participation in two rural mental health services. *International Journal of Mental Health Nursing*, 16(3), 214-222. doi: 10.1111/j.1447-0349.2007.00470.x
- Malins, G., Oakley, K. & Doyle, R. (2011). Building consumers in to service evaluation: development of the MH-CoPES Framework in New South Wales. *Australasian Psychiatry*, 19(4), 360-364. doi: 10.3109/10398562.2011.579124
- McDaid, S. (2009). An equality of condition framework for user involvement in mental health policy and

User Involvement in Mental Health Settings

planning: evidence from participatory action
research. *Disability & Society*, 24(4), 461-474. doi:
10.1080/09687590902879064

National Institute for Health and Care Excellence (2011).

*Service User Experience in Adult Mental Health:
Improving the Experience of Care for People Using
Adult NHS Mental Health Services (NICE Clinical
Guideline 136)*. Manchester: NICE.

National Survivor User Network (2014). *Service User
Involvement in the Delivery of Mental Health
Services*. London: NSUN.

NHS England (2016). *Implementing the NHS Five Year
Forward View*. London, England: NHS England.

NHS England (2017). *Next Steps on the NHS Five Year
Forward View*. London, England: NHS England.

Neech, S. (2015). User involvement in adult mental health
settings: user motivations and benefits (Doctoral
thesis, Staffordshire & Keele Universities,
Staffordshire, UK). Retrieved from
[http://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.6
78234](http://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.678234)

User Involvement in Mental Health Settings

- Pearson, Y. (2006). *Valuing Involvement: Strengthening Service User and Carer Involvement in NIMHE. Policy and Vision Statement on the Purpose of Involvement*. London: DoH.
- Petersen, K., Hounsgaard, L. & Nielsen, C.V. (2008). User participation and involvement in mental health rehabilitation: a literature review. *International Journal of Therapy & Rehabilitation*, 15(7), 306-313. doi: 10.12968/ijtr.2008.15.7.30453
- Pitt, V., Lowe, D., Hill, S., Prictor, M., Hetrick, S.E., Ryan R, et al. (2013). Consumer-providers of care for adult clients of statutory mental health services. *The Cochrane Database of Systematic Reviews*. Issue 3. Art. No.: CD004807 doi: 10.1002/14651858.CD004807.pub2.
- Restall, G. & Strutt, C. (2008). Participation in planning and evaluating mental health services: building capacity. *Psychiatric Rehabilitation Journal*, 31(3), 234-238. doi: 10.2975/31.3.2008.234.238
- Rise, M.B., Solbjør, M. & Steinsbekk, A. (2013). Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: a

User Involvement in Mental Health Settings

qualitative case study. *International Journal of Social Psychiatry*, 60(4), 387-395. doi: 10.1177/0020764013491739

Rose, D., Fleischmann, P. & Schofield, P. (2010). Perceptions of user involvement: a user-led study. *International Journal of Social Psychiatry*, 56(4), 389-402. doi: 10.1177/0020764013491739

Rose, L.E., Mallinson, R.K. & Walton-Moss, B. (2004). Barriers to family care in psychiatric settings. *Journal of Nursing Scholarship*, 36(1), 39-47. doi: 10.1111/j.1547-5069.2004.04009.x

Rutter, D., Manley, C., Weaver, T., Crawford, M.J. & Fulop, N. (2004). Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London. *Social Science and Medicine*, 58(10), 1973-1984. doi: 10.1016/s0277-9536(03)00401-5

Sani, F., Herrera, M., Wakefield, J.R.H., Boroch, O. & Gulyas, C. (2012). Comparing social contact and group identification as predictors of mental health. *British Journal of Social Psychology*, 51(4), 781-790. doi: 10.1111/j.2044-8309.2012.02101.x

User Involvement in Mental Health Settings

- Schehrer, S., Sexton, S. (2010). *Involving Users in Commissioning Local Services*. York: Joseph Rowntree Foundation.
- Slay, J., & Stephens, L. (2013). *Co-Production in Mental Health: A Literature Review*. London: New Economics Foundation.
- Soffe, J., Read, J. & Frude, N. (2004). A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health, 13*(6), 583-592. doi: 10.1080/09638230400017020
- Storm, M. & Davidson, L. (2010). Inpatients' and providers' experiences with user involvement in inpatient care. *Psychiatric Quarterly, 81*(2), 111-125. doi: 10.1007/s11126-009-9122-6
- Storm, M., Knudsen, K., Davidson, L., Hausken, K. & Johannessen, J.O. (2011). "Service user involvement in practice": the evaluation of an intervention program for service providers and inpatients in Norwegian community mental health centers. *Psychosis: Psychological, Social and Integrative Approaches, 3*(2), 29-40. doi: 10.1007/s11126-009-9122-6

User Involvement in Mental Health Settings

- Tait, L. & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 11(3), 168-175. doi: 10.1192/apt.11.3.168
- Tambuyzer, E. & Van Chantal, A. (2013). Service user and family carer involvement in mental health care: divergent views. *Community Mental Health Journal*, 49(6), 675-686. doi: 10.1007/s10597-012-9574-2
- Tweed, A. & Priest, H. (2015). Grounded theory. In: Rohleder, P. & Lyons, A.C. (Eds.), *Qualitative Research in Clinical and Health Psychology* (pp.114-132). Basingstoke: Palgrave Macmillan.
- Weinstein, J. (2006). Involving mental health service users in quality assurance. *Health Expectations*, 9(2), 98-109. doi: 10.1111/j.1369-7625.2006.00377.x
- Wilkinson, R.G. & Pickett, K. (2010). *The Spirit Level: Why Equality is Better for Everyone*. Revised ed. London: Penguin.
- World Health Organisation, Regional Office for Europe (2010). *User Empowerment in Mental Health*. Copenhagen: WHO.

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Tables

Table 1: Participant Demographics

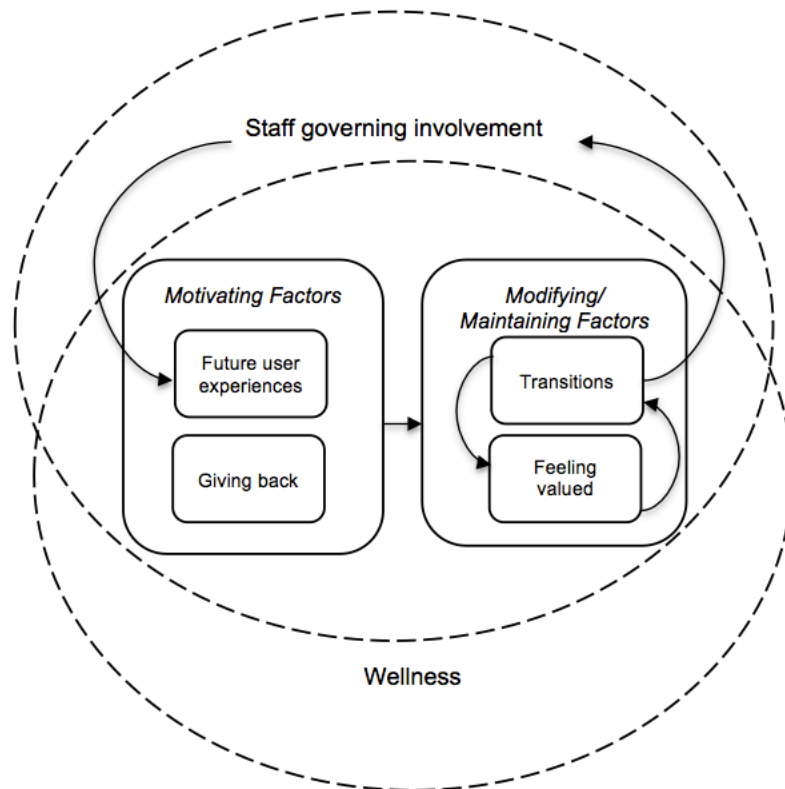
Participant	Age Range¹	Sex	Highest Educational Qualification	Duration Using Services	Duration in User Representative Role
1	30-39	M	Degree	12 years	3 years
2	30-39	F	Degree	14 years	4 months
3	30-39	F	Degree	6 years	2 years
4	60-69	M	High School	17 years	3 years
5	50-59	F	Vocational Qualification	39 years	34 years
6	50-59	F	High School	37 years	12 years
7	20-29	F	High School	11 years	6 months
8	30-39	F	Degree	20 years	2 years
9	50-59	M	Degree	18 years	15 years
10	51-59	F	Vocational Qualification	2 years	3 months
11	60-69	M	Masters	59 years	18 months
12	60-69	F	Masters	10 years	3 years
13	50-59	F	Degree	15 years	8 years

¹ Age ranges, rather than actual ages, are reported to ensure individual participants cannot be identified from the demographic data.

Figures

Figure 1

Conceptual Framework of *Being a User Representative*



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