

**User Involvement in Adult Mental Health Settings:
User Motivations and Benefits**

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Preface

This Doctorate in Clinical Psychology (D.Clin.Psy.) thesis explores user involvement within adult mental health services. Although many terms are used to describe the role of individuals who access and give their time to support mental health services, such as ‘consumer advocate’ and ‘service user consultant’, the most common terms in the identified literature, ‘users’, ‘user representative’, and ‘user involvement’ will be used in this thesis to provide consistency.

Two user/carer representatives were involved in the research process detailed throughout this thesis, assisting with development of research questions, ethical considerations, recruitment, analysis, and dissemination of findings.

The thesis starts with Paper 1, *Factors to be Considered When Users Participate in Adult Mental Health Service Development: A Review of the Literature*. Paper 2 describes the empirical grounded theory study conducted to explore *Experiences of User Involvement in Mental Health Settings: User Motivations and Benefits*. *My Journey with Action Research* (Paper 3) documents the full genesis of the project, its action research nature, and incorporates reflections from throughout the research process.

Paper 1 has been written with the intention of submitting for publication in *The Patient*, a journal for the study of patient-centred outcomes research, which has published a number of user involvement studies. Paper 2 has been written with the intention of submitting for publication in *Health Expectations*, a journal for the study of user involvement. Despite being highly relevant to the topic of Paper 2, the journal’s limitations include a small word limit. Therefore, more detail regarding action research, grounded theory, and user involvement within the study has been included in Paper 3.

Although the journals have different requirements, the Vancouver style referencing used within this thesis is in keeping with author guidelines for *Health Expectations* and reference lists from recent papers published within

the journal, to provide consistency. It is acknowledged that prior to submitting the papers for publication, changes will be required to referencing and layout.

Thesis Abstract

User involvement within healthcare settings has been increasingly prevalent in recent years, where individuals accessing services contribute to their development and delivery. This thesis describes the process of exploring user involvement in adult mental health settings. A review of the literature highlighted that despite government calls for additional emphasis on user involvement to improve services, a number of barriers stop meaningful involvement from being enacted. To avoid tokenism in user involvement practices, power differentials need addressing, and users need to see tangible change as a result of their involvement activities. There has been limited research into users' motivations for taking on an involvement role within an organisation, yet this is key to understanding criteria for successful involvement. To explore the role of user representatives, including motivations and personal gains, a study informed by action research was developed in collaboration with users of mental health services. Semi-structured interviews with thirteen user representatives were analysed using constructivist grounded theory techniques. The resultant themes highlighted initial motivating factors for user representatives including wanting to give back to services, and making a difference for future users. Experiences of involvement depended on wellness and whether user representatives felt valued. The theme of transition captured shifts in identity, yet staff ultimately governed user involvement activities. Clinical implications are discussed in light of findings, with particular emphasis on the clinical psychology profession. However, development of infrastructure and teams to address specific areas of service development should include staff, user representatives, and users from all levels of an organisation. Further research is suggested to examine the links between user involvement and wellbeing, and dynamics between staff and user representatives to address power relations.

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Paper 1: Literature Review

Factors to be Considered when Users Participate in Adult Mental Health Service Development

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Abstract

Involving users in the feedback and monitoring of mental health services has become increasingly prevalent in recent years, enabling users to obtain greater autonomy and influence. However, governments call for additional emphasis on user involvement to improve services. The aim of this review is to summarise existing knowledge from empirical studies regarding user involvement in service development, within statutory and non-statutory adult mental health settings. Ten studies were critically reviewed, assessing rigour, credibility, and relevance. A narrative review and thematic analysis were performed to describe the data, identify themes, and synthesise findings. Two main categories were identified with three sub-themes for each: studies focusing on views and perspectives (with the themes of tangible change, representativeness of users, and power differentials), and studies focusing on outcomes of user involvement (with the themes of a focus on process, individual agendas, and disempowerment of frontline staff). Differences in expectations and unclear routes of accountability and decision-making were apparent among organisational leaders, users, and frontline staff. An illusion of power-sharing was apparent, where users were involved in service development, but not necessarily in a meaningful way. Services need to engage with staff and users at different organisational levels to define the process of involvement, including desired outcomes and criteria for success.

Key Points for Decision Makers

- Although organisational leaders, staff, and users agree that user involvement is valuable in service development, the process can leave users and frontline staff feeling disempowered.
- Clarity of role, criteria for success, feeling connected to decision-making, and seeing tangible change are vital within user involvement.
- Task forces to address specific areas of service development should include staff and user representatives from all levels of an organisation.

Introduction

Listening to the voice of users, understanding identified needs, and making changes in response, are elements fundamental to the future success of healthcare organisations. The role of the user representative is considered vital in achieving more effective mental health services.¹⁻³ By removing barriers and power differences between individuals, communities, services, and governments, users are given an opportunity for their voice to be heard, and encouraged to obtain greater autonomy and influence.⁴

Historically, user involvement in the UK started with networks in the 1970s, where users of mental health services advocated for their rights, and challenged stereotypes associated with mental health.^{5,6} In the 1980s, early user forums enabled groups of users to meet for mutual peer support. During this period four major user networks formed to provide support, information, and advocate for users of mental health services: the UK Advocacy Network, Survivors Speak Out, National Voices Network, and the Hearing Voices Network.⁶

Since the 1990 *National Health Service (NHS) and Community Care Act*,⁷ user involvement has been a requirement within UK NHS organisations. The *NHS Act*,⁸ *Local Government and Public Involvement Act*,⁹ *Health and Social Care Act*,¹⁰ *The NHS Plan*,¹¹ and *National Service Framework for Mental Health*,¹² highlight the importance of consulting users of health services, with emphasis on users' roles as consultants and stakeholders in service change and development.

The last decade has seen a call for mental health services to provide more influence and choice for users,^{13,14} and the National Institute for Mental Health England's involvement framework¹⁵ recommends involvement structures become embedded within services. There is recognition that the NHS must become more responsive to user needs and wishes^{8,9,16} and include users in the development and monitoring of services.¹⁷ Developing users' knowledge, skills, confidence, and leadership, and embedding user involvement within organisations to determine formal links to HR, finance,

and governance,^{15,18} are seen as means to redress user influence and provide effective systems of engagement.¹⁹

The National Institute for Health and Care Excellence (NICE) reaffirms this message, and in 2011 developed clinical guidance, *Service User Experience in Adult Mental Health*.³ NICE state that feedback from mental health users should be used to monitor and improve services, and that users should be involved in the planning and delivery of mental health and social care training. *No Health Without Mental Health*¹³ suggests a greater emphasis on user involvement within the determining of priorities, planning of local services, and development of anti-stigma activities, all of which may contribute to an individual's recovery by addressing discrimination and power differentials. Investigations into major failings within health services resulted in the *Transforming Care* report,²⁰ 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*²¹ also suggested that the Care Quality Commission consider having users inspect care providers, to prevent poor practices within health care settings, and put systematic checks in place to hear and respond to user experiences.

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, was identified in a recent literature review to improve social inclusion, address stigma, improve skills, and aid prevention and wellbeing.²² Within the profession of clinical psychology, user involvement is central to improving services, developing guidelines,²³⁻²⁵ and understanding mental health difficulties.²⁶ It has potential therapeutic gains for individual user representatives, encouraging greater social inclusion and aiding recovery.^{2,13,22,27} In *New Ways of Working for Applied Psychologists in Health and Social Care*¹ the British Psychological Society (BPS) recommend

user involvement be situated within multi-disciplinary team (MDT) settings. Within MDTs, users would have involvement in their own care planning, designing service information literature, providing staff training, and have representation at team meetings, staff away days, and development meetings. Adult mental health users can have direct practice involvement with services, being employed in user participation development posts, providing advocacy, and facilitating or co-facilitating support or therapeutic activities. The BPS suggest clinicians need to facilitate involvement by providing opportunities for feedback using satisfaction questionnaires and outcome scales, and by supporting user-led service monitoring, as well as user involvement that contributes to staff selection and appraisal.

Recent changes to user involvement policy and practice have meant adult mental health organisations approach the need for user input in service development in different ways. This review brings together recent literature regarding user involvement in adult mental health settings, exploring the enactment of user involvement in service development. It is hoped that by reviewing experiences of user involvement and service development, clinical psychologists and other mental health professionals will consider their role in implementing meaningful user involvement in service development, in order to redistribute power and connect with psychological wellbeing.

Aims

With the wealth of guidance and legislation surrounding user involvement in the past ten years, this paper aims to review the most recent literature on user involvement. In particular, this literature review aims to understand the ways users can be involved in service development within adult mental health services, and asks the question: What factors need to be considered when users participate in adult mental health service development?

The Review Process

Search Process and Strategy

The following search strategy was developed in consultation with a specialist health librarian. Considering the recent national and international policy changes and requirements relating to involvement, a timeframe of 2004-2014 was set. This review focuses on the implementation of user involvement in mental health services, where organisations had put user involvement into practice in relation to service development. Papers that captured views regarding the implementation of such activities were included, where the focus of research was on how to involve users in service development. Where an English translation was available international papers were included, if the knowledge produced was seen as transferable to a UK setting (i.e. the type of involvement activities presented could be used in community and inpatient NHS settings). Thus, including learning and good practice identified from mental health services worldwide.

Inclusion Criteria

The review includes peer-reviewed empirical research studies that explore the explicit role of users in adult mental health service development. The following criteria were used as limiters as part of the search strategy: the studies should review involvement or views on implementation of involvement activities, be within statutory or non-statutory adult mental health settings, relevant to a UK setting, and be in English.

Databases and Other Sources

The NHS Evidence Healthcare Databases Advanced Search (HDAS) and major database, EBSCO, were used to search the following databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medline, Embase, PsychInfo, Allied and Complementary Medicine Database (AMED), and Academic Search Complete (ASC). For the review to be as up to date as possible, search alerts were set up on all databases from June-October 2014. Reference lists of identified papers were also scanned to identify any omissions.

Search Terms

Key words used to conduct the search were “service user involvement”, and other words identifying this concept, in combination with a search for mental health services. The search string is shown in Box 1. Where possible (dependent on the database), search terms were linked to database subjects.

(“patient participation” OR “patient representatives” OR “consumer-driven health care” OR “mental health services – citizen participation” OR “service user involvement” OR “client participation” OR “patient and public involvement” OR “patient involvement” OR “user involvement” OR “client involvement”) AND “mental health services”

Box 1. Search String

Search Outcome and Retrieval of Data

The initial search revealed 309 references, which were checked for duplicates, reducing the number to 238.

Determining Relevance

All references were screened by title and abstract. Studies were excluded if the focus was on peer support, involvement in an individual’s own care, or involvement in training or research (where although service development may have been an outcome, it was not the main activity and process being examined), leading to the exclusion of 207 references. The remaining 31 papers were read in full, which led to the exclusion of 21 references for the following reasons: involvement activities that did not specifically mention service development, involvement in individual care, national guideline development (where users were not involved directly in developing the service they had used), research was not relevant to UK settings, and research that involved users but where involvement was not the focus of the study. Hand searching from bibliographies and author citations was performed iteratively, and introduced an additional five references; however, these did not meet the final criteria for the review, as they did not explicitly examine the process of user involvement in adult mental health settings.

Ten studies were included in the final literature review (see Appendix A for flow diagram of exclusion process).

Quality Appraisal

All ten papers identified described qualitative research or questionnaire-based research (with quantitative elements). The Critical Appraisal Skills Programme for qualitative research²⁸ (Appendix B) and Greenhalgh's *Checklist for a Qualitative Research Paper*²⁹ (Appendix C) were used to critically appraise the qualitative studies in the review. Greenhalgh's *Checklist for a Paper Describing Questionnaire Research*²⁹ (Appendix C) was used to critically appraise the questionnaire-based studies. The checklists aiding the appraisal process were used in order to assess the rigour and credibility of the studies.

Data Extraction and Analysis

Due to the qualitative nature of the majority of studies within the review, a comprehensive narrative synthesis was conducted.³⁰ An initial synopsis of each of the ten papers, including study aim, setting, and type of user involvement, research design/methods, and review of findings was written and summarised in table form (Appendix D and E). After a critical appraisal of each paper,^{28,29} thematic analysis³¹ was undertaken, followed by a synthesis incorporating discussion of the major themes and issues of importance, using objective conclusions based on the literature reviewed.³⁰

Findings

Of the ten studies relating to user involvement in adult mental health service development, two explored involvement in voluntary sector agencies, eight focused on involvement in statutory mental health services, and four drew on experience and views from independent user groups.

Synopses and Critical Review of Individual Studies

Crawford and Rutter's research³² in London inpatient and community services explored whether views of user group members reflected those of

users not in a representative role. Their study was a result of findings from a previous study,³³ where mental health staff stated user groups were not representative of the patient population, and user representatives identified this perception as the main barrier within involvement. A questionnaire identifying service development priorities and suggestions was given to self-appointed user group members (n=8) and staff (n=38), and results were compared to findings from a random sample of users in an on-going audit of patient satisfaction within the same services (n=90). Using ANOVA to compare overall priority ratings for different stakeholders, the authors found all participant groups identified similar priorities (although staff rated employment and training as more important than users). User group members rated all options as a higher priority, and made more spontaneous comments than users. Despite a high response rate overall (79-89% for users, user group members, local managers, and consultant psychiatrists), only 50% of Trust board members completed the questionnaire. As board members are responsible for service development decisions, it seems this study is limited by poor representation of this group.

Horrocks et al³⁴ sent questionnaires to users and carers of statutory adult mental health services in Lancashire, UK, asking for demographic information and qualitative responses to the question 'Tell us what you think is most important for good mental health services'. Participants' questionnaire results (n=103) were analysed using a cyclical reflective process, where concepts, codes, and themes were developed and discussed. The themes were used to analyse documents including agendas, actions plans, and minutes from partnership board meetings over a 12-month period (where user involvement had occurred). Family and friends, access, control and respect, and work activity were salient themes for users. The partnership board spent most time on giving information, processes and actions, involvement of users and carers, commissioning, and service issues. Evidence of outcomes and actions within the meetings related mostly to individual users, rather than service development. The authors acknowledged their influence on the research process by displaying reflexivity regarding the role they played in identifying themes, and having an

‘insider understanding’, as they were present at partnership meetings as staff members. However, they did not reflect on contextual factors or ethical considerations that impacted their findings, and it is therefore unclear whether approval was sought from an ethics committee, or if any issues were raised during the study.

Perceptions of user involvement in rural Australian mental health services were the focus of a study by Kidd et al,³⁵ examining the enactment of user involvement policy. User representatives involved in service development via attendance at a steering group (n=2), and clinicians (n=8), participated in semi-structured interviews, which were analysed using qualitative descriptive methodology. Both groups encountered barriers including ambivalence, users’ continuing mental health difficulties, payment for users’ time, and the funding of involvement generally. The authors found an overarching metaphor of ‘dynamic of change’, identifying the need for systemic change to the way user involvement is funded and incorporated into mental health services. This study had the advantage of returning transcripts to participants, to confirm faithful accounts of their meaning. However, there were low numbers of user representatives participating, and the research lacks the user voice. The authors did not report their role within the services, potentially missing the impact of power relations and pre-existing relationships that may have influenced findings.

The equality of condition framework uses dimensions of inequality (such as power, resources, and solidarity) to explain how individuals working together are not necessarily equal.³⁶ McDaid³⁷ explored the experience, or anticipated experience, of user involvement on advisory committees, by mapping findings onto the equality of condition framework. Semi-structured interviews were conducted with users at an Irish non-statutory mental health organisation (n=15) and leaders of the national user movement (n=5). Grounded theory analysis was used to develop categories of inequality, including cultural resources, physical and mental resources, unequal time, economic resources, and lack of respect, recognition, and power. The study situated involvement within wider equality debates, encouraging a social

approach to mental health and service development. McDaid's study recognised the researcher's role, and was more collaborative than other studies, by involving users in the research process. However, it is unclear how saturation of data was reached, and if theoretical frameworks other than equality of condition were considered (and thus, whether findings were grounded in data, a key element of grounded theory methodology).

Restall and Strutt³⁸ recruited users from diverse geographic and socio-cultural environments in Manitoba, Canada, via mental health services and user groups, to research facilitation of meaningful involvement in service development. Participants attended semi-structured interviews (n=26) or focus groups (n=37). As part of coding and analysis a conceptual framework (informed by grounded theory) was presented, to include the need for development of a respectful, inclusive, and flexible user involvement processes, and activities that support, promote, and connect to service decisions. Their findings highlighted the need for services to invest time in involvement, and that tangible outcomes were more likely to lead to positive change. A strength of the study included an interim summary being sent to participants (n=30), who were invited to comment, to triangulate sources. However, no quotes from the data were used to evidence findings, making it difficult to know how the framework was developed, and whether it was grounded in data.

Rise et al³⁹ set out to investigate the experience of participating in the implementation of a user involvement development plan, devised collaboratively by multidisciplinary groups including administrators, health professionals, and user representatives in a mental health community hospital in Norway. The plan, part of a reorganisation process, included the establishment of a patient education centre, user representative office, outcome management system, purchasing user expertise, quality assurance of attitudes and culture among personnel, and improving communication and informational materials. Semi-structured interviews were conducted with user representatives (n=4) and professionals (n=13), and authors observed meetings where implementation of the plan was discussed. Thematic

analysis with a constant comparative technique identified three narratives; success (where users and professionals felt planning initiatives were established, increasing the user involvement focus), success despite obstacles (where professionals acknowledged the complex organisational structure, centralised decision-making, and insufficient permeation), and limited success (highlighting responsibility and decision-making, understanding, tokenism, and where user involvement was in competition with other tasks). This study benefited from triangulation of data from different sources, with data collection ceasing at theoretical saturation (where no new information is felt to be coming from the data). However, more staff than users participated in the study, potentially missing the user experience. Authors did not report outcomes for users not in a representative role, which is another limitation of this study, as the impact upon current users is unclear.

To explore the impact users perceive involvement to have on service development in two London boroughs, Rose et al⁴⁰ conducted semi-structured interviews and questionnaires with user representatives from local user groups (n=20), and users from mental health day centres (n=20). To analyse data, the authors used thematic analysis of interviews (although the method of this is unclear) and quantitative analysis (Fisher's exact test, $p < 0.05$) for questionnaires. The study reported little difference between representatives' and users' perceptions of involvement outcomes, with 92% of participants agreeing that user involvement improved services. User representatives were aware of different aspects of user involvement, and were more specific in their answers, referring to a wider range of barriers, including stigma, tokenism, power, and inequality. The study benefited from being user-led. Being users of mental health services themselves, Rose et al considered their influence and interest in the area of user involvement. Local users assisted with the questionnaire design and conducted interviews, another strength of the study, with some attending research skills training, enabling coproduction of knowledge.

To identify stakeholders' perspectives, and models of user involvement implemented within adult mental health services in two NHS Trusts in London, Rutter et al⁴¹ held semi-structured interviews with staff (n=27), voluntary sector user group members (n=9), and Trust user representatives (n=13). Observations and minutes from Trust meetings incorporating user involvement were used as data sources to identify objectives regarding user involvement, the extent to which these had been achieved, and factors influencing implementation. Grounded theory analysis found user representatives focused more on desired individual changes, particularly in relation to their own negative experience, and were opposed to Trusts selecting users to 'represent' the views of others. Managers focused on the process of user representation to support managerial functions and decision-making. Nurses were more ambivalent, expressing reservations and resentment of involvement activities. Nurses perceived an added burden, being the targets of complaints, with no expertise to implement changes, and where users' views were given more credibility than those of staff. Although triangulation of data sources is a strength of this study, by including current users of services as participants the study would have benefited from an additional perspective. Little information being provided regarding saturation of data within the grounded theory process, and the authors' roles within the services also limits this study.

A user involvement intervention programme was delivered at community mental health centres for users with long-term mental health problems in Norway. The programme included seminars, workshops, individual and group work, meetings, development of an action plan, and a plenary session for inpatients, family members, and staff. Storm et al⁴² compared questionnaire responses from staff (n=78) and users (n=17) at two centres that had received the intervention with responses from staff (n=108) and users (n=29) at three centres that had not. The authors used statistical analysis, regression, to confirm the intervention was the strongest predictor on staff reports of organisational user involvement ($p < 0.05$). The intervention was not associated with inpatient experience, involvement in treatment, or satisfaction of inpatient stay. Despite the study benefiting from

comparison site questionnaires, rather than relying on case study data, limits to this study include greater numbers of staff than users contacted, and a low user response rate (224 staff were contacted, with a response rate of 83%, and 110 inpatients with a response rate of 43%).

Staff and users of a UK non-statutory mental health day centre conducted two separate quality assurance (QA) processes to assess user involvement in evaluation and service development. Weinstein⁴³ used documents, reflections, and observations to undertake a comparative case study of processes and outcomes of two approaches to engaging mental health users in the QA process. The first QA process (1998) was described as directive from management, with less ownership from users and staff, demonstrating the meeting of organisational standards. The later QA process (2000), in comparison, was seen as collaborative, with staff and users agreeing an action plan and monitoring process, with a user-led agenda. In the study, the author examined Likert-scale questionnaires completed by users during the first (n=21) and second (n=51) process, although neither data nor results were reported. Although the author's reflexivity situates the study within its case study context, highlighting her role as a staff member in both processes, the study was retrospective, and therefore did not intend to compare the two processes, resulting in non-comparable data. The study was limited by a low response rate from the first QA process (28% of users completed the questionnaire, from the 75 contacted). As part of an action research process, users were part of the second QA process and contributed to the case study, adding strength and emphasising user voices in the research.

Synthesis

To effectively compare studies and conduct a thematic analysis, the papers were re-read and coded for the type of knowledge they set out to find. After grouping codes together, categories began to develop, that were re-named to best capture the overall categories. The ten papers were organised into two categories: research exploring views and perspectives of user

involvement in service development (Category 1),^{32,35,37,38,40} and research addressing outcomes of user involvement in service development (Category 2).^{34,39,41-43}

Construction of descriptive themes, followed by analytical themes, were developed in each of the categories, drawing on guidance from Thomas and Harden,⁴⁴ and Aveyard,³¹ regarding thematic synthesis in literature reviews. The results of each study were hand-coded for themes summarising the main findings, in relation to the literature review question. Each paper contained several themes, which developed and were re-named to best capture the overall themes in the two categories. Within Category 1 (views and perspectives) the themes of tangible change, representativeness, and power differentials were developed. A focus on process, individual agendas, and disempowerment of frontline staff were the themes developed within Category 2 (outcomes).

Category 1 (Views and Perspectives)

This category consisted of five papers focusing on the views and perspectives in relation to users' involvement in mental health service development (Appendix D). All five studies aimed to compare perspectives in relation to involvement, and included data from users with experience of involvement activities. Four studies explored the views of current users not engaged in user involvement,^{32,37,38,40} and three studies accessed professionals' perspectives.^{32,35,38} One study aimed to explore the experience of service development involvement,³⁷ two explored how services enacted user involvement in service development,^{35,38} and two investigated whether users involved in service development held views representative of users generally.^{32,40}

Theme 1 (Tangible Change)

Thematic analysis highlighted that users needed to see tangible change to view their contribution as worthwhile. If change was not visible the process was considered tokenistic in nature. In one study user involvement was seen to legitimise decisions that had already been made by service

providers.³⁸ User representatives wanted to see specific changes to services,^{32,40} and in the study by Rose et al,⁴⁰ user representatives saw service development priorities as more important than other users. From the user representative perspective, the effort and time involved could be great and the change itself small, yet worthwhile if the impact was visible.³⁸ Lack of clarity regarding involvement roles in existing involvement structures was attributed to not achieving tangible change, as staff and users were unable to define expectations, and therefore unable to define clear activities and outcomes associated with involvement roles.³⁵

McDaid's³⁷ use of the equality of condition framework to explain how user representatives are disadvantaged in comparison to professionals highlights the need for resources, respect, recognition, and power to enable change. Rather than services fitting involvement into existing structures, Kidd et al³⁵ call for a new infrastructure, making involvement fundamental to the system to facilitate meaningful involvement and tangible change. They propose changing organisational culture by paying user representatives for their involvement activities, and establishment of career pathways for user representatives, to legitimise users as team members.

Restall and Strutt³⁸ present a conceptual framework for participation as a result of their study, where users need to connect to decisions made as a result of participation activities. They suggest that by communicating how participation activities influence service planning, delivery, policy formation, and evaluation, facilitation of participation in service development will be more effective. User representatives in the study by Rose et al⁴⁰ felt that feedback from services on user involvement was poor, and providers need to do more to suggest how participation activities influence services. Restall and Strutt³⁸ call for a definition of user involvement that does not merely describe an exchange of information, but actually includes activities where a direct connection between the activity and service decision is apparent.

Theme 2 (Representativeness)

The studies by Crawford and Rutter³², and Rose et al,⁴⁰ set out to explore whether users in involvement settings are representative of all users. The studies had similar findings, with users and user representatives identifying similar priorities and holding similar views regarding involvement and service development. Findings suggest user representatives can have a meaningful impact on service development by advocating on behalf of the wider user population. Although it is recognised this may not always be the case. User representatives appear to place more importance on priorities, and be more specific with their suggestions and concerns than users not in a representative role, although little difference was found regarding perceived outcomes of involvement.^{32,40} However, Horrocks et al³⁴ argue that user involvement creates an inherent contradiction, where users are considered individual 'experts by experience', yet are expected to represent other users.

Restall and Strutt³⁸ recommend that services provide a range of involvement opportunities in order to be inclusive to users who face barriers due to illness or location. They suggest the use of 'storytelling', where users share their previous experiences, and have their voice heard within a service development context. Crawford and Rutter's³² research, developed due to staff concerns over representativeness, indicates the need for services to employ different techniques, such as surveys, and to maintain strong links between user representatives and user groups, to ascertain the views of active users. If these engagement techniques were enacted, the process would serve to validate a culture of obtaining users' views, and start addressing power differentials.³²

Theme 3 (Power Differentials)

Users felt that power inequality was apparent, when involvement purely legitimised pre-made decisions,³⁸ when users were only asked for opinions on small decisions, such as ward decorations,⁴⁰ when negotiation occurred between meetings with users, leaving users out of the decisions, when a user's view conflicted with that of their clinician, and when users were

excluded due to technical language.³⁷ The use of plain language and explanation of terms was seen as key to addressing initial struggles with power.^{37,38} Services need to find a way of enabling user voices to be perceived as providing specialist knowledge in the same way as other professional groups. In order to achieve this, Kidd et al³⁵ suggest developing systems whereby users become stakeholders in services in their own right, where their specialist knowledge is valued and required as part of user involvement initiatives and service evaluations.

Restall and Strutt³⁸ suggest building interpersonal relationships between professionals and users, sharing resources, and offering tangible support to address power differentials. They also stress that flexibility in processes is vital to supporting users in contribution to service development, yet it is important not to exclude users from key events. Therefore, holding committee meetings when at least two user representatives are present may impede decisions being made without user input.³⁷

Staff may experience conflict, such as difficulties viewing a user as an individual with a mental health difficulty at the same time as having the capacity to offer expert knowledge, and there are questions as to whether the two roles are mutually exclusive.³⁵ Formal affirmation of the value of lived experience within service development by stating its importance during committee meetings,³⁷ key stakeholders developing shared understanding of user involvement initiatives, promoting specific initiatives that increase valued user involvement, and providing funding for user involvement at a government and service level,³⁵ may help to address power differentials.

Category 2 (Outcomes)

This category consisted of five papers, focusing on outcomes related to user involvement in service development, using a case study approach, where implementation of user involvement was studied in real-life settings (Appendix E). Three studies sought data from users not in involvement roles,^{34,42,43} three sought data from staff,^{39,41,42} and two sought data from

user representatives.^{39,41} Four of the studies incorporated minutes or observations of meetings where user representatives were present.^{34,39,41,43} Two papers examined outcomes of initiatives designed to enhance user involvement,^{39,42} two examined evidence of change resulting from involvement,^{34,41} and one compared quality assurance (QA) processes.⁴³

Theme 1 (Focus on Process)

Within the studies reviewed, organisational leaders faced pressure to enact governmental policy or good practice guidance, and top-down processes in relation to user involvement were enacted in an attempt to meet short timescales for compliance. At times, when user involvement was implemented in mental health services, it did not infiltrate to service delivery, or impact current user experience.^{34,39,41-43} Some studies attributed this to lack of available resources^{34,39,41} or time taken up with discussion of the involvement process,^{34,39,41} referred to as 'consultation' rather than participatory involvement.⁴¹ The requirement for users to integrate into pre-existing organisational management procedures was apparent. Service planning and development often occurred outside of meetings with users, and users were not invited to discuss certain clinical issues, such as restraint.⁴¹ Some Trusts had specifications to recruit 'suitable' users, as professional behaviour and language were expected, and emotional outbursts not tolerated.⁴¹

Weinstein's⁴³ comparative case study of QA processes offers an example of a shift from emphasis on the process of involvement to collaborative agenda-setting and action. By involving users from the outset, and establishing a steering group to oversee the QA process, users reported meaningful involvement. Horrocks et al³⁴ argue involvement with a process-focus creates an illusion of power-sharing, where although a symbolic commitment to involvement is apparent, better outcomes are unlikely to be reached, as influence on decisions and power dynamics are not addressed.³⁴ Rise et al³⁹ put forward a similar case, namely, more frequent involvement does not

necessarily imply genuine involvement, even when quantitative outcomes (such as numbers of users involved in service development) are met. To ensure involvement is genuine, data identifying the impact on service development, user representatives' perceptions, and current user experiences should be sought. There is an identified need for services to provide involvement opportunities at a number of levels, to fully engage users throughout processes in adult mental health services.^{39,43}

Theme 2 (Individual Agendas)

From analysis of the studies, it appears that when users were involved in service development, they had a personal agenda often associated with their own negative experience.^{34,41} Rutter et al⁴¹ highlight that user representatives in their study wanted to become independent of services, with a completely user-defined agenda, user-only forums, and independent funding, to address power differentials and have less reliance on staff.

Weinstein⁴³ found that users were more concerned with quality of life than service development priorities, and that involvement fostered development of individual specific changes, relating to users' needs. The study by Rise et al³⁹ indicated individuals in the same service hold contrasting views regarding success of user involvement.

To see user involvement as a benefit in service development, the criteria for success and understanding of involvement needed to be clarified, as an individual's understanding of involvement influenced whether they considered the process successful.³⁹

Theme 3 (Disempowerment of Frontline Staff)

Some studies discovered that frontline staff felt disempowered and undermined regarding user involvement.^{41,43} Findings from the study by Rutter et al⁴¹ suggest nurses' ambivalence, reservations, and resentment were based on concerns around being unskilled, having extra burden, and that users' views were valued more than their own. The authors argue that

promoting nurse empowerment may be more effective than training for addressing perceived staff threats.⁴¹ However, staff training on user involvement is suggested by others,³⁴ and was the focus of some studies regarding implementation of user involvement.^{39,42}

In Weinstein's study,⁴³ staff representatives on a steering group with user representatives and organisational leads, addressed staff disempowerment by discussing different priorities from the beginning of the QA process. Having equal numbers of users and staff on the steering group, as well as representatives from independent user groups (not run by mental health services), also supported the attempt to empower individual users and staff members.⁴³

Discussion

Analysis of the literature regarding user involvement in mental health service development has indicated the importance of establishing clearly defined roles and expectations within user involvement activities. Organisational leaders, frontline staff, and users appear to have different agendas and expectations, resulting in confusion and ambivalence regarding involvement, and lack of clarity and structure where involvement can occur.

Organisational leaders implementing policy and governmental guidance seem to focus on the process of involving users. User representatives appear to focus on specific change relating to personal circumstances. Frontline staff, in the middle of this process, can experience uncertainty, finding it difficult to situate themselves within involvement practices, potentially seeing users as both patients and 'experts'. This may question a professional's own identity, their role as a staff member, and the value of their participation in service development, where services may focus on obtaining the views of users over staff. This consideration may influence relationships within teams and dynamics within user involvement initiatives.

Power inequalities are apparent on a number of dimensions within user involvement. Governmental policy dictates the necessity for involvement,

and organisational leaders appear responsible for the process by which this is enacted within services. As a result, frontline staff and users feel somewhat disempowered, with unclear lines of accountability and decision-making responsibility. There is an illusion of power-sharing connected to involvement, and organisations may achieve quantitative outcomes and targets without meaningful involvement or tangible change occurring.

Some studies indicated that users with involvement roles represented the views of other users, and held similar views and priorities.^{37,40} The desirability of the user representative role is debatable, as user representatives are not necessarily required to share their own lived experience, but rather take advocacy roles. In one study users were against services selecting individuals to represent all users of a service,⁴¹ and user representatives do not appear to be elected because of their ability or desire to represent others. It appears user representatives had an increased desire to change services, and placed greater emphasis on priorities than users not in a representative role. The motivation for becoming involved in service development may be more closely related to negative personal experiences. An implication of this may be increased conflict and disagreement with staff in committee meetings, as users want their difficulties with the service addressed, therefore being perceived as blaming professionals. In some cases, other forums such as patient liaison services, or feedback and complaints teams, may be best placed to provide support on these issues.

Being witness to tangible change gave meaning to users involved in service development. Only with tangible change was user involvement seen by users as meaningful, and not tokenistic. Where tangible change was seen, scepticism regarding involvement as a means to justify already-made decisions was alleviated. Organisation leaders, in comparison, placed greater value on providing involvement than witnessing tangible outcomes.

In order to address top-down processes, power differentials, and ambivalence regarding user involvement in service development, organisations need to engage staff and users at different levels. This

includes strategy, planning, training, committees, and team meetings. Work initially needs to include defining the process of involvement within the organisation, including the desired outcomes and criteria for success for users, staff, and organisational leaders. Previous literature suggests involvement is more effective when users are asked what role they wish to take regarding involvement.²⁷ Implementation of this process, with clear decision-making and action planning, need to be integrated into all organisational levels. This process of definition could be explored within organisational infrastructure, and on a smaller-scale for service development in particular areas, by contacting users of specific services for their views, providing involvement opportunities for those wishing to support service development. Research into user involvement outside service development suggests the powerlessness felt by providers and users decreases when users help define outcomes and complete specific actions, rather than being part of a large involvement committee.⁴⁵ Staff members and user representatives need to work together, as a task force for example, on specific areas of service development, where clear service improvement goals are agreed on and enacted, with adequate resource allocation. Where this is not possible, establishing working relationships with independent user groups may be more effective. Financial support, training, and user involvement policies may already be established among independent groups, providing validity and respect for the user perspective from an early stage in the service development process.

Within the field of clinical psychology, clinicians need to work with multi-disciplinary colleagues to recognise the therapeutic value of user involvement, and impact on recovery. Clinical psychologists can support individual users to attribute meaning to experiences of mental health difficulties, and incorporate involvement experiences into understanding of the self. In addition, clinical psychologists may identify service development issues, such as introducing new therapeutic pathways or approaches into a team or organisation, and provide opportunities for partnership and collaboration from users from the outset. These tasks should be recognised

as an opportunity to incorporate or establish user involvement within specific mental health service development activities.

To understand how user involvement in mental health settings can be implemented effectively, it is important to recognise why users choose to devote their time to such activities. Future research could explore user motivations, expectations, and personal outcomes achieved within user involvement roles. Further exploration into how organisations establish a culture of user involvement, and set up an appropriate infrastructure to incorporate the user perspective in a service development context, may also be of value. A comparison of the input of user groups and user representatives within an organisation would add to knowledge regarding the effectiveness of different forms and governance of user involvement. In addition, research could explore links between user involvement and the recovery model,⁴⁶ increasingly being introduced within mental health services, where rather than treating or managing symptoms, users are actively engaged in self-discovery and personal growth. It would be interesting to consider the role of service development involvement activities in wellness recovery action plans^{47,48} for users of mental health services.

Conclusion

Engaging users of mental health services in service development is valued within many organisations, yet there are challenges associated with achieving meaningful involvement. Users and staff face issues such as different expectations, power inequalities, and questions over representativeness. Users need to see tangible change as a result of their participation, however involvement initiatives within organisations may focus more on consultation of users and the process of involvement, rather than action planning and implementation of service changes.

These findings call for a collaborative approach to user involvement, engaging staff and users at different levels in mental health services for specific service development initiatives.

References

1. British Psychological Society. *New Ways of Working for Applied Psychologists in Health and Social Care – Working Psychologically in Teams*. Leicester: BPS, 2007.
2. Tait L, Lester H. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 2005; **11**: 168-175.
3. National Institute for Health and Care Excellence. *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, 2011.
4. World Health Organisation Regional Office for Europe. *User Empowerment in Mental Health*. Copenhagen: WHO, 2010.
5. Rose D, Fleischmann P, Tonkiss F, Campbell P, Wykes T. *User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature*. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO). London: HMSO, 2004.
6. Wallcraft J, Bryant M. *The Mental Health Service User Movement in England. Policy Paper 2*. London: The Sainsbury Centre for Mental Health, 2003.
7. HMSO. *National Health Service and Community Care Act 1990. Chapter 19*. London: HMSO, 1990.
8. HMSO. *The National Health Service Act 2006. Chapter 41*. London: HMSO, 2006.
9. HMSO. *The Local Government and Public Involvement in Health Act 2007 (Commencement No. 1 and Savings) Order 2007, Chapter 125, Article 2(a)*. London: HMSO, 2007.
10. HMSO. *Health and Social Care Act. Chapter 15*. London: HMSO, 2001.

11. Department of Health. *The NHS Plan*. London: DoH, 2000.
12. Department of Health. *A National Service Framework for Mental Health*. London: DoH, 1999.
13. Department of Health. *No Health Without Mental Health*. London: DoH, 2011.
14. HMSO. *Equity and Excellence: Liberating the NHS*. London: HMSO, 2010.
15. Health and Social Care Advisory Service. *Making a Real Difference: Strengthening Service User and Carer Involvement in NIMHE: Final Report*. London: HASCAS, 2005.
16. Bardsley D. *Valuing Involvement: Strengthening Service User and Carer Involvement in NIMHE. Policy for Involving Service Users and Carers*. London: DoH, 2006.
17. Pearson Y. *Valuing Involvement: Strengthening Service User and Carer Involvement in NIMHE. Policy and Vision Statement on the Purpose of Involvement*. London: DoH, 2006.
18. National Survivor User Network. *Service User Involvement in the Delivery of Mental Health Services*. London: NSUN, 2014.
19. Schehrer S, Sexton S. *Involving Users in Commissioning Local Services*. York: Joseph Rowntree Foundation, 2010.
20. Department of Health. *Transforming Care: A National Response to Winterbourne View Hospital: Department of Health Review Final Report*. London: DoH, 2012.
21. HMSO. *Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry*. London: HMSO, 2013.

22. Slay J, Stephens L. *Co-Production in Mental Health: A Literature Review*. London: New Economics Foundation, 2013.
23. Harding E, Brown D, Hayward M, Pettinari CJ. Service user perceptions of involvement in developing NICE mental health guidelines: a grounded theory study. *Journal of Mental Health*, 2010; **19**: 249-257.
24. Harding E, Pettinari CJ, Brown D, Hayward M, Taylor C. Service user involvement in clinical guideline development and implementation: learning from mental health service users in the UK. *International Review of Psychiatry*, 2011; **23**: 352-357.
25. Soffe J, Read J, Frude N. A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health*, 2004; **13**: 583-592.
26. Hossack A, Wall G. Service users: undervalued and underused? *The Psychologist*, 2005; **18**: 134-136.
27. Storm M, Edwards A. Models of user involvement in the mental health context: intentions and implementation challenges. *Psychiatric Quarterly*, 2013; **84**: 313-327.
28. Public Health Resource Unit. *Critical Appraisal Skills Programme (CASP): 10 Questions to Help You Make Sense of Qualitative Research*. 2013. [cited 2015 Apr 13]. Available from: http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf
29. Greenhalgh T. *How to Read a Paper: The Basics of Evidence-Based Medicine*. 4th ed. Chichester: Wiley-Blackwell, 2010.
30. Green BN, Johnson CD, Adams A. Writing narrative literature reviews for peer-reviewed journals: secrets of the trade. *Journal of Chiropractic Medicine*, 2006; **5**: 101-117.

31. Aveyard H. *Doing a Literature Review in Health and Social Care: A Practical Guide*. 3rd ed. Berkshire: Open University Press, 2014.
32. Crawford MJ, Rutter D. 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*, 2004; **13**: 561-569.
33. Crawford MJ, Aldridge T, Bhui K, Rutter D, Manley C, Weaver T, et al. User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. *Acta Psychiatrica Scandinavica*, 2003; **107**: 410-414.
34. Horrocks J, Lyons C, Hopley P. 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*, 2010; **34**: 562-569.
35. Kidd S, Kenny A, Endacott R. Consumer advocate and clinician perceptions of consumer participation in two rural mental health services. *International Journal of Mental Health Nursing*, 2007; **16**: 214-222.
36. Baker J, Cantillon S. *Equality; From Theory to Action*. Basingstoke: Palgrave Macmillan, 2004.
37. McDaid S. An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research. *Disability & Society*, 2009; **24**: 461-474.
38. Restall G, Strutt C. Participation in planning and evaluating mental health services: building capacity. *Psychiatric Rehabilitation Journal*, 2008; **31**: 234-238.
39. Rise MB, Solbjør M, Steinsbekk A. Experiences from the implementation of a comprehensive development plan for user involvement in a mental

health hospital: a qualitative case study. *International Journal of Social Psychiatry*, 2013; **60**: 387-395.

40. Rose D, Fleischmann P, Schofield P. Perceptions of user involvement: a user-led study. *International Journal of Social Psychiatry*, 2010; **56**: 389-402.

41. 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. *Social Science and Medicine*, 2004; **58**: 1973-84.

42. Storm M, Knudsen K, Davidson L, Hausken K, Johannessen JO. "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*, 2011; **3**: 29-40.

43. Weinstein J. Involving mental health service users in quality assurance. *Health Expectations*, 2006; **9**: 98-109.

44. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology* [cited 2015 Apr 13]. Epub 2008. Available from: doi: 10.1186/1471-2288-8-45

45. Broer T, Nieboer AP, Bal R. Mutual powerlessness in client participation practices in mental health care. *Health Expectations*, 2014; **17**: 208-219.

46. Gould D. *Service Users' Experiences of Recovery Under the 2008 Care Programme Approach*. London: NSUN, 2012.

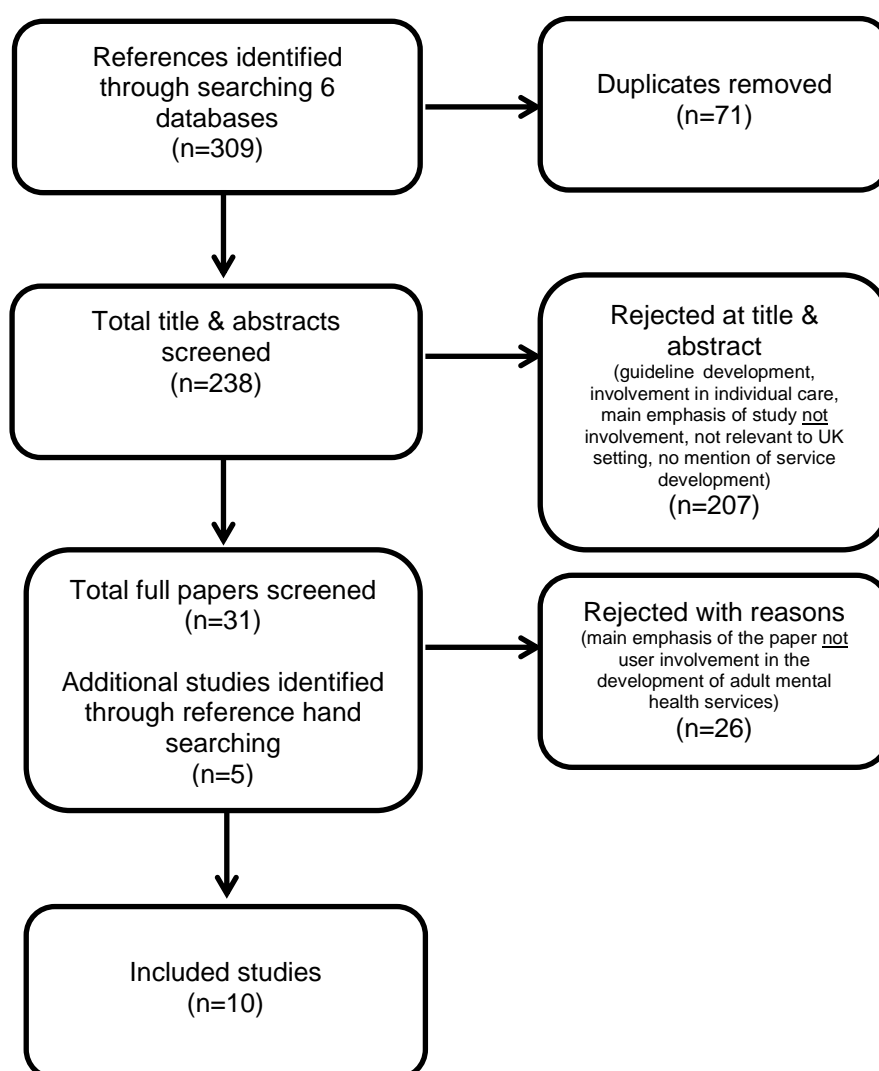
47. Fukui S, Starnino VR, Susana M, Davidson LJ, Cook K, Rapp CA, et al. Effect of Wellness Recovery Action Plan (WRAP) participation on psychiatric symptoms, sense of hope, and recovery. *Psychiatric Rehabilitation Journal*, 2011; **34**: 214-222.

48. Cook JA, Copeland ME, Floyd CB, Jonikas JA, Hamilton MM, Razzano L, et al. A randomized controlled trial of effects of Wellness Recovery Action Planning on depression, anxiety, and recovery. *Psychiatric Services*, 2012; **63**: 541-547.

49. Springer. *The Patient - Patient-Centered Outcomes Research*. 2015. [cited 2015 Apr 11]. Available from:
<http://www.springer.com/adis/journal/40271>

Appendices

Appendix A: Flow Diagram of Search Process



Appendix B: Critical Appraisal Skills Programme (CASP) Tool²⁸



10 questions to help you make sense of qualitative research

How to use this appraisal tool

Three broad issues need to be considered when appraising the report of a qualitative research:

- Are the results of the review valid?
- What are the results?
- Will the results help locally?

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions.

There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

These checklists were designed to be used as educational tools as part of a workshop setting

There will not be time in the small groups to answer them all in detail!

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Screening Questions

1. Was there a clear statement of the aims of the research?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- What was the goal of the research?
- Why it was thought important?
- Its relevance

2. Is a qualitative methodology appropriate?

☐ Yes ☐ Can't tell ☐ No

HINT: Consider

- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal?

Is it worth continuing?



Detailed questions

3. Was the research design appropriate to address the aims of the research?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher has justified the research design (e.g. have they discussed how they decided which method to use)?

4. Was the recruitment strategy appropriate to the aims of the research?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

5. Was the data collected in a way that addressed the research issue?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the setting for data collection was justified
 - If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
 - If the researcher has justified the methods chosen
 - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, or did they use a topic guide)?
 - If methods were modified during the study. If so, has the researcher explained how and why?
 - If the form of data is clear (e.g. tape recordings, video material, notes etc)
 - If the researcher has discussed saturation of data
-

6. Has the relationship between researcher and participants been adequately considered?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during
 - (a) Formulation of the research questions
 - (b) Data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

7. Have ethical issues been taken into consideration?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

8. Was the data analysis sufficiently rigorous?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

9. Is there a clear statement of findings?

☐ Yes

☐ Can't tell

☐ No

HINT: Consider

- If the findings are explicit
 - If there is adequate discussion of the evidence both for and against the researchers arguments
 - If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
 - If the findings are discussed in relation to the original research question
-

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding e.g. do they consider the findings in relation to current practice or policy?, or relevant research-based literature?
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Appendix C: Checklists for Finding, Appraising, and Implementing Evidence

Checklist for a qualitative research paper²⁹

1. Did the article describe an important clinical problem addressed via a clearly formulated question?
2. Was a qualitative approach appropriate?
3. How were (a) the setting and (b) the participants selected?
4. What was the researcher's perspective, and has this been taken into account?
5. What methods did the research use for collecting data – and are these described in enough detail?
6. What methods did the researcher use to analyse the data – and what quality control measures were implemented?
7. Are results credible, and if so, are they clinically important?
8. What conclusions were drawn, and are they justified by the results?
9. Are the findings of the study transferable to other clinical settings?

Checklist for a paper describing questionnaire research²⁹

1. What did the researchers want to find out, and was a questionnaire the most appropriate research design?
2. If an 'off-the-peg' questionnaire (i.e. a previously published and validated one) was available, did the researchers use it (and if not, why not)?
3. What claims have the researchers made about the validity of the questionnaire (its ability to measure what they want it to measure) and reliability (its ability to give consistent results across time and within/between researchers)? Are these claims justified?
4. Was the questionnaire appropriately structured and presented, and were the items worded appropriately for the sensitivity of the subject area and the health literacy of the respondents?
5. Were adequate instructions and explanations included?
6. Was the questionnaire adequately piloted, and was the definitive version amended in light of pilot results?

7. Was the sample of participants appropriately selected, large enough and representative enough?
8. How was the questionnaire distributed (e.g. by post, email, telephone) and administered (self-completion, researcher-assisted completion), and were these approaches appropriate?
9. Were the needs of particular subgroups taken into account in the design and administration of the questionnaire? For example, what was done to capture the perspective of illiterate respondents or those speaking a different language from the researcher?
10. What was the response rate, and why? If the response rate was low (less than 70%), have the researchers shown that no systematic differences existed between responders and non-responders?
11. What sort of analysis was carried out on the questionnaire data, and was this appropriate? Is there any evidence of 'data dredging' – that is, analyses that were not hypothesis driven?
12. What were the results? Were they definitive (statistically significant), and were important negative and non-significant results also reported?
13. Have qualitative data (e.g. free text responses) been adequately interpreted (e.g. using an explicit theoretical framework)? Have quotes been used judiciously to illustrate more general findings rather than to add drama?
14. What do the results mean and have the researchers drawn an appropriate link between the data and their conclusions?

Appendix D: Table of Included Studies (Category 1: Views and Perspectives)

Reference	Study Aim	Setting & Type of Involvement	Research Design, Method & Sample	Analysis	Major Findings/ Main Themes
Crawford & Rutter (2004) ³²	To explore whether views of user group members reflect those of 'ordinary' patients. To compare these with the views of local service providers.	Inpatient and community services. London, UK. Monthly user group, with self-appointed members who attend management and planning meetings, and are part of recruitment panels.	Questionnaire to identify priorities and suggestions for service development. Random sample of users from on-going audit (selected using sampling frame from hospital database) (n=90), local user group members (n=8), local managers (n=25), consultant psychiatrists (n=8), and members of the Trust board (n=5).	Mean ratings for each item (priority) calculated for each group of stakeholders. Fisher's exact test used to compare proportion of different groups who made spontaneous comments about changes to services. ANOVA used to compare overall priority ratings means for different stakeholders.	User group members and patients identified similar priorities and views in relation to service development. User group members rated all priorities higher than users not in representative role. Staff reported similar priorities and views, but rated employment and training as more important than other groups. User group members were more likely than users to make spontaneous comments in response to open-ended questions.
Kidd et al (2007) ³⁵	To explore concepts/perceptions of 'consumer participation' held by clinicians and consumer advocates. To examine how participation policy is being enacted.	Two rural mental health services. Victoria, Australia. Consumers with formal advocate role, within services and on steering group committee (which guides development of services, including structures through which consumer participation enacted).	Individual semi-structured interviews (broad questions regarding consumer participation to specific service level examples). Consumer advocates (n=2) and clinicians (n=8) recruited from steering committees of both services.	Data analysis informed by qualitative descriptive method. Line-by-line coding, clustering themes, and interpretations. Development of a thematic network, global themes, and overarching metaphor.	Consumers and clinicians encountered ambivalence and faced barriers, including challenge of continuing illness, remuneration, and funding. Overarching metaphor identified as 'dynamic of change'.
McDaid (2009) ³⁷	To explore the experience, or anticipated experience, of participation on advisory committees, using the equality of condition framework as a lens to situate involvement within wider equality debates, contributing to development of a social approach to mental health.	National mental health non-governmental organisation (NGO). Ireland. Participation on advisory committees, and part of the development and delivery of advocacy training programme.	Individual semi-structured interviews (set of open, non-directive questions structured around key themes). Part of larger participatory action research project (PAR) (participants involved in research design and analysis). Core group of mental health users (involved in PAR project) selected by snowballing at NGO (n=15). Leaders of Irish user/survivor selected via snowballing (n=5) for data source triangulation.	Qualitative analysis using grounded theory techniques. Inductive categories generated and organised along the equality of condition framework.	Participation mapped against dimensions on equality of condition framework, including: unequal cultural resources, unequal physical and mental resources, unequal time and economic resources, and lack of respect, recognition and power.

Reference	Study Aim	Setting & Type of Involvement	Research Design, Method & Sample	Analysis	Major Findings/ Main Themes
Restall & Strutt (2008) ³⁸	To explore how health planners can facilitate involvement in a meaningful and effective way in service and policy development.	Mental health services and consumer groups. Manitoba, Canada. Mental health service planning and evaluation.	Focus groups and individual semi-structured interviews (participants given choice of participation method except in remote locations where focus groups were not feasible). Mental health users with and without service planning and evaluation experience, recruited from service providers and consumer groups for individual interviews (n=26) and focus groups (n=37).	Coding scheme based on interview guide used to generate codes and sub-codes using line-by-line coding and memo writing. Coded by one author and reviewed by another. Interim summary of analysis sent to participants (n=30), who were invited to send back comments/attend a workshop.	Conceptual framework of participation developed regarding participation activities, including development of a respectful, inclusive, flexible process, and activities that support, promote and connect to decisions. Involvement activities need time invested and tangible outcomes leading to positive change.
Rose et al (2010) ⁴⁰	To explore the impact users think involvement has on the services they use, and whether user representatives and 'non-activists' perceptions of user involvement differ.	Local user groups and day centres. Two London boroughs, UK (both going through change processes). Attendance at user group meetings.	Individual semi-structured interviews and questionnaire (primarily closed questions, with some opportunities for participants to expand on answers). Activists recruited from local user groups (n=20) and non-activists from day centres (n=20).	Quantitative analysis of closed questions using Fisher's exact test (p<0.05). Thematic analysis of open questions, supported by qualitative software program MaxQDA.	Activists more aware of local user groups and each aspect of user involvement than non-activists (with exception of user involvement in research, where there was no difference). Little difference of perceptions of outcomes of user involvement among groups. User representatives' comments were more specific, pointing to a wider range of issues (including stigma, tokenism, power and inequality).

Appendix E: Table of Included Studies (Category 2: Outcomes)

Reference	Study Aim	Setting & Type of Involvement	Research Design, Method & Sample	Analysis	Major Findings/ Main Themes
Horrocks et al (2010) ³⁴	To examine the participation of user and carer members of local partnership board, and to look for evidence of their influence in priority setting and decision making.	Three local authorities, five primary care Trusts, and a mental health Trust. Lancashire, UK. User representatives on the board (involvement group set up to support user and carer participation in board activities).	Case study approach. Questionnaire (to establish user and carer priorities). Examination of partnership board agendas, action plans, minutes, and the user and carer involvement group minutes over a 12-month period. Postal/email questionnaire sent to users (n=103) on a contact database and in local networks/groups, as well as being posted on partnership website.	Questionnaire scrutinised independently, then analysed using a cyclical reflective process. Team discussions used to examine concepts, codes, and themes. Themes became the coding structure for thematic analysis of the partnership meeting documents, describing activity/focus of discussion.	Top themes for users were: family and friends, work activity, control, respect, and access. The partnership board spent most time on process and actions, giving information, involvement of users and carers, commissioning issues, and service issues. Outcomes related to individual users, rather than service development.
Rise et al (2013) ³⁹	To investigate the experience of professionals and user representatives taking part in implementation of a user involvement development plan.	Mental health community hospital. Central Norway. Implementation of a development plan to enhance user involvement in the hospital. Data collection stopped at theoretical saturation.	Case study approach. Semi-structured interviews with individuals who had taken part in implementation process (using topic guides regarding the implementation process and cooperation between users and professionals). Observations of ten meetings where implementation process was discussed. Interviews with user representatives (n=4), and professionals, including psychiatrists, psychologists, and mental health nurses (n=13).	'Scientist as a traveller' framework used for thematic analysis. Coding framework developed with list of basic codes using NVivo. Constant comparison with transcripts provided meaning, condensation and interpretation. Observational data supported of categories and interpretation of 'stories'.	Three narratives/'stories' identified: the story of success was heard from both users and professionals (with planning, initiatives established and increased focus on user involvement), the story of success despite implementation obstacles was heard mostly by professionals (with acknowledgement of complex organisational structure, centralised decision-making and deficient anchoring and permeation), and the story of limited success (which highlighted responsibility and decision-making, understanding user involvement, and tokenism, where user involvement competes with other tasks).

Reference	Study Aim	Setting & Type of Involvement	Research Design, Method & Sample	Analysis	Major Findings/ Main Themes
Rutter et al (2004) ⁴¹	To identify the model(s) of user involvement implemented in local area, to identify objectives and desired outcomes and extent to which achieved, and to identify positive and negative factors influencing implementation.	Adult mental health services with two mental health provider NHS Trusts. London, UK. Management recruitment panels, user groups, forums, outreach and feedback, user development workers, and consultation.	Grounded theory approach, using semi-structured interviews (topic list amended as theory of process developed). Observations of meetings between users and managers. Analysis of documents and minutes from Trust meetings where there had been user participation. Representatives of all main stakeholders invited to interview, using snowball sampling strategy by approaching Trust employees including chief executives, senior and middle managers, consultant psychiatrists, and ward managers, with responsibility for user involvement (n=27), and local user groups within the voluntary sector (n=9), and in the Trusts (n=13). Sampling continued to ensure triangulation of major stakeholder groups.	Two researchers read transcripts of interviews and coded to develop a framework grounded in the data. Interview and meeting texts were indexed and disaggregated to relevant aspects of the coding framework.	Users and staff had different agendas for involvement. Managers focused more on the process of user representation to support managerial functions and decision-making, nurses were more ambivalent, expressing reservations and resentment in relation to involvement activities, and users focused more on desired change identified by individual users (negative experiences were central to motivation for involvement and empowerment of an oppressed group), and were against Trusts selecting users to 'represent' the views of others.
Storm et al (2011) ⁴²	To assess an intervention program designed to increase attention to user involvement and increase involvement at inpatient and departmental levels. To address the implementation of user involvement in mental health services for people with long-term mental health problems.	Five community mental health centres (CMHCs). Different regions of Norway. Intervention program included user involvement seminar, with thematic analysis of user interviews, individual work, group work, and plenary session for inpatients, family members, providers, and user representatives to develop action plan. Monthly staff meetings. Five user involvement educational sessions.	Quasi-experimental design with non-equivalent comparisons (2 CMHCs assigned to the intervention – CMHC-I, 3 CMHCs participated as comparison departments – CMHC-C). Pre-measurement and post-intervention questionnaire. Questionnaires completed by CMHC-I service providers (n=78) and inpatients (n=17), and by CMHC-C service providers (n=108) and inpatients (n=29).	Statistical analysis: regression to confirm organisational user involvement (p<0.05) and patient collaboration (p<0.10), and T-tests to confirm improving carer involvement (p<0.05) and organisational involvement (p<0.001).	Intervention was strongest predictor of impact of providers' reports of organisational user involvement. A positive impact on providers' reports of patient collaboration and carer involvement also noted. No difference in relation to inpatient experiences, involvement in treatment, or satisfaction of inpatient stays.

Reference	Study Aim	Setting & Type of Involvement	Research Design, Method & Sample	Analysis	Major Findings/ Main Themes
Weinstein (2006) ⁴³	To compare the process and outcomes of two different approaches to engaging mental health users in quality assurance (QA) process.	Voluntary sector mental health day centre for minority ethnic group. UK. QA process.	Retrospective study using data from QA process in 1998 (Likert scale questionnaire) and 2000 (questionnaire), with analysis of associated QA documentation, and reflections and observations from the author (who worked within the centre). Elements of action research. Minutes of meetings, correspondence, service standards, and reports from the QA process also used. As part of the 1998 QA process a questionnaire sent to all users of the day centre; users completed a questionnaire (n=21) or attended a review day. In 2000 the QA process included principles of user-focused monitoring (users developed a list of priorities). Questionnaires completed by users of the day centre (n=51).	Examination of questionnaires and documents to compare process, methodology and outcomes of the QA processes.	Staff indicated indifference and cynicism regarding user involvement during the 1998 QA process, with no system for monitoring records. In the 2000 QA process staff and users agreed on an action plan and monitoring process, with collaborative user-led agenda, new approach to seeking users' views, and higher response rate.

Appendix F: *The Patient* Author Guidelines⁴⁹

The Patient - Patient-Centered Outcomes Research

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Aims and Scope

The Patient is a vehicle for the study of outcomes research to enhance therapy in a patient-centered manner. The journal aims to examine the needs, values and role of the patient in an increasingly complex healthcare landscape in which funding and decision making are requiring ever greater awareness of the patient's perspective. The Patient includes:

- Original research (clinical trials, observational studies, surveys, methods).
- Reviews.
- Current opinion papers.
- Correspondence.
- Editorials.

All manuscripts are subject to peer review by international experts.

The word counts given below do not include the abstract, references, figure legends or table captions.

Review Article

Word count up to 6000. Provides an authoritative, balanced, comprehensive, fully referenced and critical review of the literature.

Abstract

Please provide an abstract of 150 to 250 words. The abstract should not contain any undefined abbreviations or unspecified references. For narrative reviews, abstracts should be unstructured (i.e. no headings).

Key Points for Decision Makers

Two to three short bullet points should be provided summarizing the key findings and implications of the paper. These should be presented in non-technical language and not repeat verbatim text found in the abstract. They should be placed beneath the abstract under the heading of 'Key Points for Decision Makers'.

Citation

Reference citations in the text should be identified by numbers in square brackets.

Reference list

The list of references should only include works that are cited in the text and that have been published or accepted for publication. Personal communications and unpublished works should only be mentioned in the text. Do not use footnotes or endnotes as a substitute for a reference list.

Paper 2: Research Report

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

Word Count: 5703

Abstract

Background: Despite governmental policies and guidance promoting user involvement, meaningful involvement continues to be the subject of much debate within mental health services. Tokenism is identified as a key barrier, where competing agendas dilute the impact of user involvement.

Objective: This study aims to explore user representatives' experiences of involvement, to gain insight into motivations and personal benefits from involvement activity.

Setting and Participants: Thirteen user representatives were recruited from an NHS mental health Trust, where they were involved in activities such as staff interviews, research, and training.

Methods: Themes within semi-structured interviews were developed using constructivist grounded theory analysis. Memo-writing, process and focused coding, and core categories were used to develop the conceptual framework of being a user representative.

Results: Analysis of the data demonstrated that staff were governing involvement, and being a user representative was inextricably linked to wellness. Initial motivating factors for user representatives included themes of giving back and wanting to make an impact for future users. Experiences of involvement depended on whether user representatives felt valued, and the theme of transition captured shifts in identity.

Discussion and Conclusion: Although user representatives reported initial altruistic motivations, they experienced increased confidence, wellbeing, and establishment of personal goals. The transition towards being a professional and community member can be aligned with compassion-focused therapy, where as individuals started recovering, they moved towards forming affiliative relationships and new experiences. User involvement activities enabled individuals to develop the ability to feel compassion towards themselves and others.

Introduction

User involvement, consumer advocacy, and patient participation all describe the process of individuals getting actively involved in an aspect of health care, rather than being a passive recipient of such services. User involvement was first observed from a psychological perspective in Arnstein's Ladder of Participation,¹ where it was proposed that true participation involved redistribution of power. The theory suggested participation was often ritualistic and tokenistic, where although voices were heard, they were not necessarily given any weighting in decision-making.

Research within adult mental health services has shown that user involvement spans the entire participation ladder, including involvement in one's own care,²⁻⁴ commenting on experiences,⁵ service evaluation,^{6,7} service development,⁸⁻¹⁰ peer support,¹¹⁻¹³ staff and student training,¹⁴⁻¹⁶ guidance and program development,¹⁷⁻¹⁹ and coproduction of knowledge in research^{20,21} and in service planning and delivery.²² Debates exist around the effectiveness of user involvement, with barriers including power differentials, lack of tangible change, and continuing tokenism.^{8,17,23-26}

There has been a constant drive to engage users with involvement activities since the 1970s, where Survivors Speak Out and the Hearing Voices Network²⁷ challenged negative stereotypes of those suffering from mental health difficulties in the UK. Since 1990, user involvement has been a requirement within UK National Health Service (NHS) organisations,²⁸ with recent emphasis in response to major failings within healthcare settings encouraging a culture of feedback and improvement.^{29,30} By visibly engaging users in all levels of participation within mental health services, it is hoped that major incidents and hierarchical cultural norms, such as those at Winterbourne View and Stafford Hospital, can be avoided, and that organisations actively learn from user experience and feedback.

The World Health Organisation³¹ asserts the importance of users in mental health services adopting self-determination. They suggest users need

greater influence on social and political strategy, with involvement in decision-making and local organisational development.

User involvement has the potential to increase existing understanding of mental distress, and benefit staff and organisations by gaining different perspectives from ‘experts’ about illness and care, enabling the development of user-focused, rather than service-focused, provision.^{16,32} A review of literature on rehabilitation found involvement had a positive effect,³³ especially in relation to development of social skills³⁴ and preventing feelings of helplessness.³⁵ The review called for further research to explore how user involvement has an impact on user representatives’ wellbeing and recovery.³³

Despite governmental and policy drivers, meaningful user involvement remains an area for development within mental health services. Studies have found professionals within organisations hold differing views^{36,37} and criteria^{10,38-40} regarding successful involvement. In order to understand how user involvement in mental health settings can be most effectively implemented, it is important to acknowledge why users choose to devote their time to such activities. If users’ motivations to become involved are recognised, then the promotion of involvement to wider groups of users, to mainstream the process, could be developed. Little research currently exists regarding users’ views of involvement, and their motivations and gains regarding such activities.

Aims

People with mental health difficulties, who have become user representatives within mental health services, offer a unique perspective. Their knowledge and experience is vital to understanding motivations and definitions of personal success for involvement. Understanding the user perspective can support further promotion and normalisation of involvement as a core component of service delivery. This study set out to explore user representatives’ experiences, focusing specifically on why users choose to

get involved, and what benefits (and difficulties) they experience as a result of their involvement activities. This study also set out to address local needs and concerns in relation to user involvement, whereby participants and staff members would collaboratively develop an involvement action plan (reported elsewhere). It is hoped that this area of enquiry has the potential to improve user involvement practices, and address some of the current barriers experienced within involvement activities in mental health settings.

Method

Methodological Approach

Grounded theory asks the question ‘what is happening here?’ and seeks to discover basic social and psychological processes without forcing data into pre-conceived categories.^{41,42} This approach can be used when little is known about a topic, and when people’s experiences are being sought.⁴³ Grounded theory promotes asking questions relating to power and control, such as how processes emerge, and who controls them. Constructivist grounded theory⁴¹ was deemed a suitable approach for this study, where data is considered to be co-constructed by the researcher and participants. Charmaz’s guidelines for constructivist grounded theory⁴¹ were used throughout.

Due to grounded theory’s emergent process, researchers do not know at the start how many participants are needed to reach saturation, the point at which no new insights or ideas are found from the data.^{41,43} However, to achieve valuable qualitative research in a D.Clin.Psy. thesis, a sample of between 8-20 participants is advised.⁴⁴

Epistemological Position

The researcher (first author) took a constructivist stance⁴¹ to explore in detail user representatives’ motivations and personal outcomes for involvement activities. This epistemology considers knowledge to be constructed via social interactions, including the research process, where knowledge and truth are seen to be based on an individual’s perspective and experience.⁴¹

The researcher considered user involvement a fluid concept, where participants (and researchers) would generate ideas and understanding through the process of research, and categories and themes would be constructed through interaction with the data.^{41,45}

Recruitment

Participants were recruited from an NHS mental health Trust in the West Midlands region of England, after relevant approvals were obtained (see Appendix A-C). Recruitment took place during an annual user and carer celebration day in the Trust, where researchers had a stand and spoke to people about the research. Participants were also recruited via existing involvement networks within the organisation, where the researcher spoke at the two user forums to explain the study. Staff responsible for user involvement within the Trust sent an email to all user representatives registered on their system to promote the study. A snowballing technique was also employed, where user representatives were asked to pass on details of the study to other user representatives (past or present). In each instance of recruitment, information packs were given, comprising of an information sheet and contact form (Appendix D and E). A freepost envelope was provided when contacted in person. Individuals interested in participating returned their contact details to the researcher, and a follow-up phone call or email confirmed participation and established an interview date.

Procedure

Thirteen user representatives participated in semi-structured interviews lasting between 38-76 minutes, with six choosing to be interviewed in their own homes (where the local lone worker policy was followed), and seven in a private room within Trust premises. Consent was gained on the day of the interview, where after the research was explained and participants had been through the information sheet (Appendix D) with the researcher, they signed a consent form (Appendix F). Interviews followed a guide developed by the researcher and user representatives on the research team (Appendix G) that explored the following areas: reasons for starting the role, personal

outcomes and achievements, positive and negative elements of the role, and suggestions for improvements locally. Participants were told they could stop at any time if they did not want to continue, and were given a support sheet at the end of the interview (Appendix H).

Analysis

Transcription of interviews used a qualitative system,⁴⁶ and any identifying information was removed at this stage to maintain anonymity. The researcher's initial coding generated active statements to describe processes within each line of the transcripts. A list of focused codes was produced by grouping the initial codes into common themes, and continually comparing them with the data using the grounded theory constant comparison method.⁴³ See Appendix I for examples of grounded theory coding.

Memo-writing assisted with analysis of focused codes, where the researcher's thoughts on connections between participant experiences and processes occurring within the role of user representative, were captured. Each memo was given a name, definition, and selection of illustrative quotes from the data (see Appendix J for example memos). Theoretical sampling was used to adjust future interview guides (Appendix G), where initial analysis informed further data collection by identifying modifiers (factors that might change a behaviour or process), and question what was still left to know. Memos were reconstructed several times, and connections made between focused codes before final categories and a conceptual framework were reached, which the researchers considered to best represent the data.

To ensure the researcher's interpretations were grounded in the data, user representatives on the research team were consulted at each step of the process, and given small non-identifiable excerpts to code (after participating in a grounded theory workshop). The researcher attended a grounded theory group with other trainee clinical psychologists, where small sections of transcripts were peer-coded.⁴³ The user representatives on the research team were able to acknowledge how their own experiences (different to that

of the researcher) influenced interpretation of the data, yet each research team member's coding was similar, indicative of analysis grounded in data.

Reaching saturation in a time-limited study is challenging, and some argue that this can never be fully achieved.⁴⁷ Interviews ceased once a level of saturation of categories was reached, and participants confirmed the final conceptual categories, although it is acknowledged there may have been more to uncover.

All participants were later invited to attend a group to feedback findings of the study, assisting with triangulation by asking for thoughts on themes and categories. Participants attending the group (n=5) considered how the information could be used at a local level to make improvements to user involvement (see Paper 3).

Participants

The thirteen participants interviewed (Table 1) self-identified as being a current or past user of adult mental health services, and a current or past user representative within the organisation (a defined role, requiring training). Participants had all taken part 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 a salaried user involvement role in the Trust and local voluntary sector organisations (although all participants were entitled to sessional fees for involvement activities in line with the Trust's involvement policy).

Participant	Age Range ¹	Sex	Employment Status	Highest Educational Qualification	Duration (Years) Using Services	Services Used	Duration in User Representative Role
1	30-39	M	Student	Currently studying towards degree	12	Psychiatrist, group therapy, community psychiatric nurse (CPN)	3 years
2	30-39	F	Part-time work Volunteer	Degree	14	Psychiatrist, substance misuse	4 months
3	30-39	F	Full-time work	Degree	6	Eating disorders, psychological services, inpatient	2 years
4	60-69	M	Long-term ill health	High school	17	Psychological services, counselling	3 years
5	50-59	F	Part-time work	NVQ-4	39	Psychiatrist, psychodrama, inpatient	34 years
6	50-59	F	Long-term ill health	High school	37	Inpatient, counselling	12 years
7	20-29	F	Volunteer	AS Levels	11	Eating disorders, inpatient	6 months
8	30-39	F	Volunteer Student	Currently studying towards degree	20	Psychiatrist, psychological services, CPN	2 years
9	50-59	M	Full-time work	Degree	18	Psychological services, psychiatrist	15 years
10	51-59	F	Long-term ill health	NVQ-3	2	Psychiatrist, inpatient	3 months
11	60-69	M	Retired Student	Masters	59	CPN	18 months
12	60-69	F	Long-term ill health	Masters	10	Psychological services, inpatient, substance misuse	3 years
13	50-59	F	Long-term ill health	Degree	15	Psychiatrist, psychological services	8 years

Table 1 Participant Demographics

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

Findings

The constructivist grounded theory process resulted in development of the conceptual framework presented in 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 transitions individuals make between different stages of being a user representative.

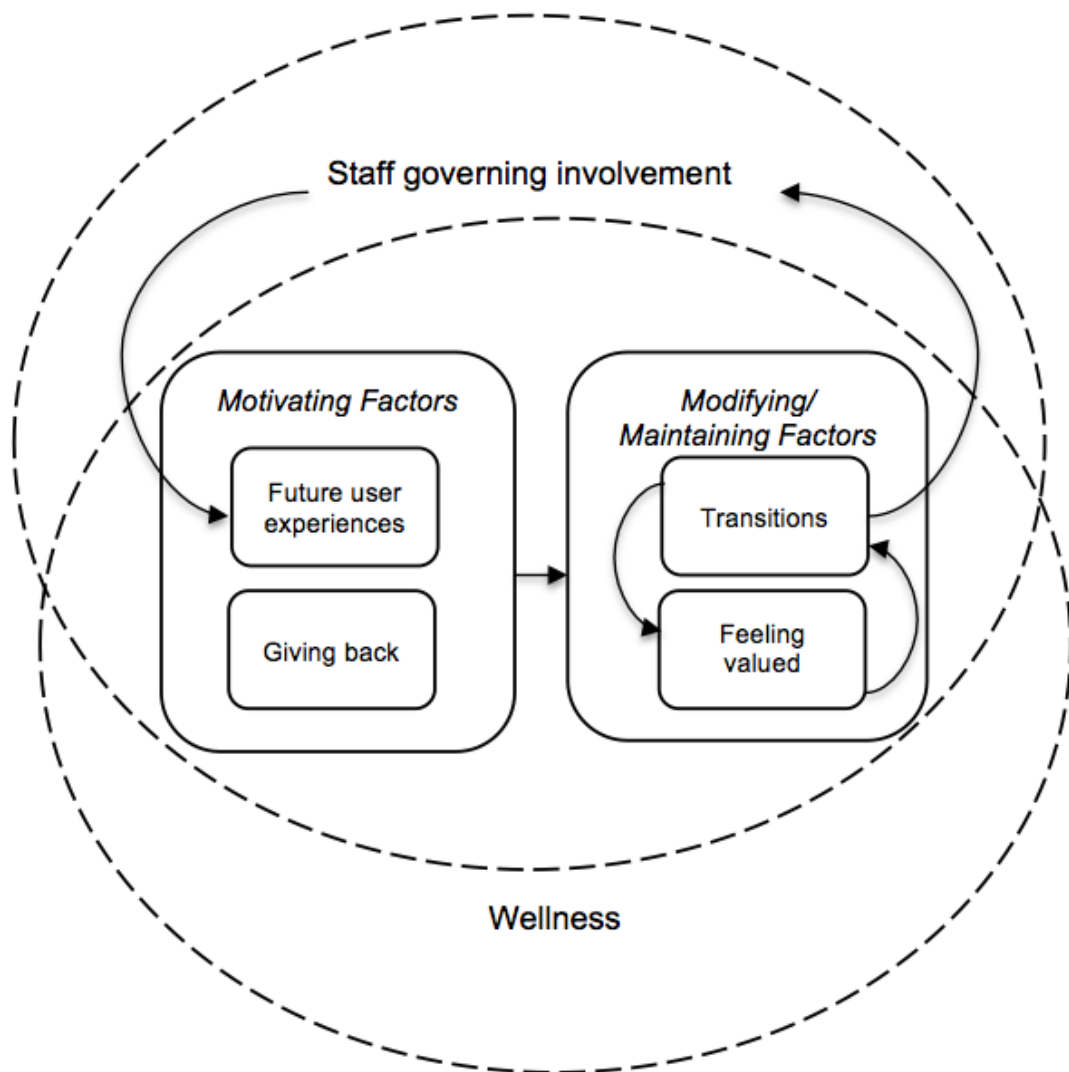


Figure 1 Conceptual Framework of *Being a User Representative*

Overarching Themes

Staff Governing Involvement

Staff members' power over user involvement was apparent in the study, 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 available.

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 and equality 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. One participant spoke about no longer having

staff representation at a user group, impacting the influence the group could have, with no staff member to take actions further within the Trust.

[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 mentioned 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)

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 an interview panel for a member of staff:

That 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

Participants felt they had received care from others, and wanted to reverse this role. For some, 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 a 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 or help-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)

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 the 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 being a user and staff member.

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 her wellbeing, and wanting to get more 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 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 very fact that involvement existed was symbolic of the value of lived experience. Value 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, on the whole payment 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 the outcome of involvement. In cases where they felt their views had not been listened to, users were less likely to feel valued, instead 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

From the data it is apparent that staff govern involvement opportunities, as without individual staff members prioritising involvement it would not have much prominence within the mental health service. Within this study 62% of participants had, or were working towards, higher education qualifications, yet this does not represent the general mental health user population. In 2008-9, only 3% of all adult mental health NHS users on a care-programmed approach reported being in employment, and 6% identified as 'other', which included being in education or training.⁴⁸ If participants in this study are characteristic of user representatives generally, it may be that staff with involvement responsibilities invite users similar to themselves (those who are educated and have understanding of conventions and professionalism) to take part in involvement activities, potentially silencing and disempowering users who do not meet this criteria. The power and control staff have over user involvement is a constant dilemma in the effort to avoid tokenism,^{10,23}

yet positive results have been seen in organisations where staff receive training on how to involve users in service development, adopting system-wide involvement.^{39,49}

As user representatives start their role, they move from seeing themselves as a 'user' to becoming more of an 'insider', where their own identity shifts towards being a staff member or contributing community member. Some user representatives transition to wanting a career in mental health, with involvement responsibilities. Some hope that cultural change will occur, where lived experience will hold greater value when staff have personal experience of mental health difficulties.

During this transitional period, user representatives notice differences to their mental health, illustrated in the overarching theme of wellness. Involvement has a positive impact, increasing confidence and opportunities for meaningful social activity. For some users involvement can negatively impact their wellbeing, where existing mental health difficulties are maintained from pressure, short time-scales, and high expectations (held by the organisation and users themselves). There is also the question of whether user representatives are really representative of those using services. This is an issue considered in previous studies,^{9,24,25} 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. However, a vast number of individuals are subsequently not represented. There is also a debate over whether personal and emotional responses are valid within involvement activities.²³ Part of moving forward, and the shift in identity, is the sense of giving back to staff and services, with the implication that individuals can consider the impact of their own experiences on others.

Helping users becomes part of an identity shift, from care-receiving to care-giving, and is a major driver in relation to motivations for starting involvement activities. 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.

Influencing the experiences of future users and giving something back are initial motivations for starting involvement activities. Previous literature supports this idea, where user representatives use involvement opportunities to rectify wrongs occurring during their own treatment, in order that others do not encounter similar problems.^{9,10}

To continue involvement activities it is important for user representatives to feel valued by the service. Seeing the impact of their involvement has a part to play, and previous studies have highlighted the importance of seeing tangible change^{24,25} and feeling connected to decisions.⁸ Payment for involvement activities, and staff respecting lived experience, also contribute to feelings of value. In previous research where users were involved in meaningful involvement processes they experienced increased confidence and self-esteem.³⁹ In this study, when user representatives felt valued they reported increased confidence, and having further engagement in involvement activities, as individuals moved away from the 'user' identity, towards recovery. Consequently, perceptions of user representatives change, whereby individuals are increasingly seen as staff members, yet able to relate to the user experience, and representatives are more likely to get their voice heard, have influence, and promote change. Previous literature suggests staff may find this process difficult,¹⁰ and experience conflict when encountering users in an expert role.⁵⁰

Group identification, including feelings of belonging and commonality, are beneficial to mental health, and likely to protect from mental health difficulties over time.^{51,52} User representatives in the study mentioned the benefits of engaging with involvement activities and meeting people on a regular basis. They also spoke of the shift from care-receiving to care-giving, and being able to recognise others' perspectives. Compassion-focused therapy (CFT),⁵³ an increasingly used approach across adult mental health settings, highlights the benefits of giving and receiving care, and achieving a sense of connectedness with others. The therapeutic approach draws on attachment theory,⁵⁴⁻⁵⁶ and can be used in this study to see how the Trust may act as a base in which user representatives can explore their new identity and pursue

goals. Compassion can be described as sensitivity to suffering, but with committed action to its prevention,⁵⁷ and Gilbert proposes that individuals need to learn to take joy from other people's accomplishments, whilst having their views perceived as valid and important.⁵⁸ The components of self-compassion defined by Neff,⁵⁹ self-kindness (rather being self-critical), seeing one's suffering as part of common humanity (rather than perceiving it as isolating), and mindfulness (rather than over-identifying with painful thoughts and feelings) can also help explain how individuals and services can support user involvement in an attempt to provide more compassionate care and services.

First, individuals move away from the reasons for presenting to mental health services (threat-focused and safety-seeking behaviours), and move towards establishing affiliative relationships, where they can be compassionate towards themselves and others, and experience feelings of value⁵⁷ (linking to the themes of transitions and feeling valued). As individuals come to the point in their treatment where they consider perspectives of others, share experiences, and try positive activities related to sense of self, user involvement can act as a means to engaging new experience-seeking behaviours.⁵⁸ The Trust may be the secure base to which user representatives return to gain support and protection, while exploring a new sense of confidence and proximity to professionals. Involvement encourages greater social inclusion,³² and as user representatives engage in pro-social relationships with others, feel increasingly valued, wanted, and respected, they develop empathy towards current users, and begin to practice compassion for others. This has therapeutic gains for the individual, and increases self-compassion⁶⁰ (linking to the theme of wellness), which differs from self-esteem by developing a kind and connected way to relate to oneself in instances of imperfection, thus increasing emotional resilience.⁵⁹ By acknowledging that pain and failure are part of the human condition⁵⁹ user representatives become less isolated and are open to consider others' perspectives, thus developing a less egocentric view.⁵⁷

Prior to involvement, during periods of mental distress, user representatives positioned themselves as different from staff, and as part of a hierarchical system within the organisation and wider society. Research suggests that socially constructed hierarchies impact on psychological health and wellbeing,⁶¹ however in this study, as involvement activities commenced, representatives noticed the 'us and them' gap narrowing. With this redistribution of power, involvement can be seen to move up Arnstein's ladder,¹ where participation in mental health services becomes more of a partnership between users and staff.

User involvement has clear benefits to the individuals involved, especially when user representatives feel valued in the role. By providing a supportive social environment where users can foster affiliative cooperation with others, and begin to develop a new identity that assimilates a care/help-giving role, user representatives feel safe to explore new experiences and possible futures.

Clinical Implications

Staff need to support user involvement, where organisations invest in a more robust infrastructure that ensures involvement includes adequate support, with resources and professionals available to help user representatives make links to their recovery and wellbeing. Clear communication regarding the impact of user involvement can promote value and respect of the user representative role, and highlight tangible changes from involvement activities. Professionals need to be actively committed in order to facilitate meaningful change, and recognise the altruistic and personal gains users can achieve through involvement, as part of their recovery journey.

Mental health professionals may want to consider the connections between therapy and user involvement, incorporating both into a collaborative recovery plan. Understanding the processes of CFT, or other psychological interventions, in order to understand the mechanisms shaping successful

user involvement, should be seen as a training need for staff leading on user involvement within mental health organisations.

Limitations

The limitations of this study include reports of user representatives from one single organisation, not necessarily representing larger groups of individuals engaged in user involvement. The user representatives interviewed may not be representative of all user representatives, but rather highly educated individuals, all of whom had access to mental health services, and who were confident and well enough to participate in research and involvement activities. Furthermore, past representatives no longer involved with the Trust were not represented within the sample, 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 group settings. Furthermore, the study's findings are limited to the sample, and may not be generalisable to other populations such as children, young people, and individuals with a learning disability.

Future Research

To further explore the links between user involvement and wellbeing, a quantitative study could test the conceptual framework regarding individual therapeutic benefits of involvement activities. By using a group identification scale, along with the Hospital Anxiety and Depression Scale,^{62,63} or Warwick-Edinburgh Mental Wellbeing Scale,^{64,65} links between user involvement activities and user representatives' wellbeing could be explored. The dynamics within staff and user representative relationships needs further exploration, including the ways hierarchies and power relations can be transcended to achieve meaningful user involvement. Although previous literature has identified organisational leaders' motivations for promoting involvement,^{9,10} it is unclear why individual professionals actively support involvement when others do not. Further study into clinicians' views of involvement from those who do not currently engage in such practices may

be beneficial to address lack of involvement in services. Another area for inquiry is the motivation for carer involvement, which is likely to be different from that of the user, with carers facing different needs⁶⁶ and treatment priorities⁶⁷ to users.

Conclusion

User involvement is a growing movement within mental health services, supporting positive change and contributing to less hierarchical approaches to care. However, in order to promote meaningful involvement that has positive benefits for the organisation, current users, and user representatives, the motivations and hopes of user representatives must be considered.

This study set out to explore the experience of being a user representative, primarily in relation to individual motivations and outcomes. Using a grounded theory methodology, interview data and constant comparative technique enabled the researcher to develop core categories and a conceptual framework relating to the user representative experience. The results of this study show that despite the presence of some hierarchical power relations with staff, user involvement can meet individual needs when user representatives perceive themselves as valued, witness tangible change, and are able to move forward, integrating involvement activities into their recovery. User representatives are often able to incorporate others' perspectives into their understanding of mental health difficulties and within the presence of altruistic motivations, have hopes for a different future for themselves, assimilating new aspects of care-giving and help-giving into their identity.

To achieve meaningful involvement benefitting user representatives, clinicians must be willing to support users in their journey as a representative, and provide opportunity for reflection as part of their recovery. 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

1. Arnstein SR. A ladder of citizen participation. *Journal of the American Institute of Planners*, 1969; **35**: 216-224.
2. Tambuyzer E, Van Chantal A. Service user and family carer involvement in mental health care: divergent views. *Community Mental Health Journal*, 2013; **49**: 675-686.
3. Solbjør M, Rise MB, Westerlund H, Steinsbekk A. Patient participation in mental healthcare: when is it difficult? A qualitative study of users and providers in a mental health hospital in Norway. *International Journal of Social Psychiatry*, 2013; **59**: 107-113.
4. Storm M, Davidson L. Inpatients' and providers' experiences with user involvement in inpatient care. *Psychiatric Quarterly*, 2010; **81**: 111-125.
5. Graham J, Denoual I, Cairns D. Happy with your care? *Journal of Psychiatric & Mental Health Nursing*, 2005; **12**: 173-179.
6. Malins G, Oakley K, Doyle R. Building consumers in to service evaluation: development of the MH-CoPES Framework in New South Wales. *Australasian Psychiatry*, 2011; **19**: 360-364.
7. Endacott R, Kidd S, Deacon-Crouch M, Judd F, Menzel M, Cornett M. Developing new services for eating disorders: an evaluation study. *Australasian Psychiatry*, 2006; **14**: 57-63.
8. Restall G, Strutt C. Participation in planning and evaluating mental health services: building capacity. *Psychiatric Rehabilitation Journal*, 2008; **31**: 234-238.
9. Horrocks J, Lyons C, Hopley P. 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*, 2010; **34**: 562-569.

10. 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. *Social Science and Medicine*, 2004; **58**: 1973-1984.

11. Pitt V, Lowe D, Hill S, Pictor M, Hetrick SE, Ryan R, et al. Consumer-providers of care for adult clients of statutory mental health services. *The Cochrane Database of Systematic Reviews*. [Internet]. 2013 [cited 2015 Mar 23]; Issue 3. Art. No.: CD004807 doi: 10.1002/14651858.CD004807.pub2.

12. Simpson A, Quigley J, Henry J, Hall C. Evaluating the selection, training, and support of peer support workers in the United Kingdom. *Journal of Psychosocial Nursing & Mental Health Services*, 2014; **52**: 31-41.

13. Hardiman ER. Networks of caring: a qualitative study of social support in consumer-run mental health agencies. *Qualitative Social Work*, 2004; **3**: 431-449.

14. Ng RM, Pearson V, Pang YW, Wong NS, Wong NC, Chan FM. The uncut jade: differing views of the potential of expert users on staff training and rehabilitation programmes for service users in Hong Kong. *International Journal of Social Psychiatry*, 2013; **59**: 176-187.

15. Chambers M, Hickey G. *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; 2012.

16. Simpson EL, House AO. Involving users in the delivery and evaluation of mental health services: systematic review. *British Medical Journal*, 2002; **325**: 1265-1271.

17. Harding E, Pettinari CJ, Brown D, Hayward M, Taylor C. Service user involvement in clinical guideline development and implementation: learning from mental health service users in the UK. *International Review of Psychiatry*, 2011; **23**: 352-357.

18. Harding E, Brown D, Hayward M, Pettinari CJ. Service user perceptions of involvement in developing NICE mental health guidelines: a grounded theory study. *Journal of Mental Health*, 2010; **19**: 249-257.
19. Haigh R, Lovell K, Lyon F, Duggan M. Service user involvement in the National PD Development Programme. *Mental Health Review*, 2007; **12**: 13-22.
20. Gillard S, Simons L, Turner K, Lucock M, Edwards C. Patient and public involvement in the coproduction of knowledge: reflection on the analysis of qualitative data in a mental health study. *Qualitative Health Research*, 2012; **22**: 1126-1138.
21. Kara H. Mental health service user involvement in research: where have we come from, where are we going? *Journal of Public Mental Health*, 2013; **12**: 122-135.
22. Slay J, Stephens L. *Co-Production in Mental Health: A Literature Review*. London: New Economics Foundation, 2013.
23. McDaid S. An equality of condition framework for user involvement in mental health policy and planning: evidence from participatory action research. *Disability & Society*, 2009; **24**: 461-474.
24. Rose D, Fleischmann P, Schofield P. Perceptions of user involvement: a user-led study. *International Journal of Social Psychiatry*, 2010; **56**: 389-402.
25. Crawford MJ, Rutter D. 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*, 2004; **13**: 561-569.
26. Warne T, Stark S. Service users, metaphors and team working in mental health. *Journal of Psychiatric and Mental Health Nursing*, 2004; **11**: 654-661.

27. Wallcraft J, Bryant M. *The Mental Health Service User Movement in England. Policy Paper 2*. London: The Sainsbury Centre for Mental Health, 2003.
28. HMSO. *National Health Service and Community Care Act 1990. Chapter 19*. London: HMSO, 1990.
29. Department of Health. *Transforming Care: A National Response to Winterbourne View Hospital: Department of Health Review Final Report*. London: DoH, 2012.
30. HMSO. *Report of the Mid Staffordshire NHS Foundation Trust Public Enquiry*. London: HMSO, 2013.
31. World Health Organisation Regional Office for Europe. *User Empowerment in Mental Health*. Copenhagen: WHO, 2010.
32. Tait L, Lester H. Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 2005; **11**: 168-175.
33. Petersen K, Hounsgaard L, Nielsen CV. User participation and involvement in mental health rehabilitation: a literature review. *International Journal of Therapy & Rehabilitation*, 2008; **15**: 306-313.
34. Valentine G, Jamieson B, Kettles AM, Spence M. Users' involvement in their care: a follow-up study. *Journal of Psychosocial Nursing and Mental Health Services*, 2003; **41**: 18-25.
35. Greenall P. 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*, 2006; **19**: xi-xxv.
36. Bertram G, Stickley T. Mental health nurses, promoters of inclusion or perpetrators of exclusion? *Journal of Psychiatric & Mental Health Nursing*, 2005; **12**: 387-396.

37. Soffe J, Read J, Frude N. A survey of clinical psychologists' views regarding service user involvement in mental health services. *Journal of Mental Health*, 2004; **13**: 583-592.
38. Rise MB, Solbjør M, Steinsbekk A. Experiences from the implementation of a comprehensive development plan for user involvement in a mental health hospital: a qualitative case study. *International Journal of Social Psychiatry*, 2013; **60**: 387-395.
39. Weinstein J. Involving mental health service users in quality assurance. *Health Expectations*, 2006; **9**: 98-109.
40. Storm M, Hausken K, Knudsen K. Inpatient service providers' perspectives on service user involvement in Norwegian community mental health centres. *International Journal of Social Psychiatry*, 2011; **57**: 551-563.
41. Charmaz K. *Constructing Grounded Theory*. 2nd ed. London: Sage, 2013.
42. Glaser BG. *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Mill Valley, California: Sociology Press, 1978.
43. Tweed A, Priest H. Grounded theory. In: Rohleder P, Lyons AC (eds.) *Qualitative Research in Clinical and Health Psychology*. Basingstoke: Palgrave Macmillan, 2014: 114.
44. Turpin G, Barley V, Beail N, Scaife J, Slade P, Smith JA, et al. Standards for research projects and theses involving qualitative methods: suggested guidelines for trainees and courses. *Clinical Psychology Forum*, 1997; **108**: 3-7.
45. Tweed A, Charmaz K. Grounded theory methods for mental health practitioners. In: Harper D, Thompson AR. (eds.) *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. Oxford: Wiley-Blackwell, 2012: 131.

46. King N, Horrocks C. *Interviews in Qualitative Research*. Los Angeles: Sage, 2010.
47. Dey I. *Grounding Grounded Theory: Guidelines for Qualitative Inquiry*. San Diego: Academic Press, 1999.
48. The Information Centre for Health and Social Care. *Mental Health Bulletin. Third Report from Mental Health Minimum Dataset (MHMDS) Annual Returns, 2004-2009*. London: The Information Centre for Health and Social Care, 2009.
49. Storm M, Knudsen K, Davidson L, Hausken K, Johannessen J, Olav. "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*, 2011; **3**: 29-40.
50. Kidd S, Kenny A, Endacott R. Consumer advocate and clinician perceptions of consumer participation in two rural mental health services. *International Journal of Mental Health Nursing*, 2007; **16**: 214-222.
51. Sani F, Magrin ME, Scignaro M, McCollum R. In-group identification mediates the effects of subjective in-group status on mental health. *British Journal of Social Psychology*, 2010; **49**: 883-893.
52. Sani F, Herrera M, Wakefield JRH, Boroch O, Gulyas C. Comparing social contact and group identification as predictors of mental health. *British Journal of Social Psychology*, 2012; **51**: 781-790.
53. Gilbert P. *The Compassionate Mind*. London: Constable, 2009.
54. Bowlby J. *Attachment and Loss: Volume 1. Attachment*. 2nd ed. London: Penguin Books, 1984.
55. Bowlby J. *Attachment and Loss*. London: Penguin Books, 1975.

56. Feeney BC, Thrush RL. Relationship influences on exploration in adulthood: the characteristics and function of a secure base. *Journal of Personality & Social Psychology*, 2010; **98**: 57-76.
57. Gilbert P. The origins and nature of compassion focused therapy. *British Journal of Clinical Psychology*, 2014; **53**: 6-41.
58. Gilbert P. *Compassion Focused Therapy*. London: Routledge, 2010.
59. Neff K. Self-compassion: an alternative conceptualization of a healthy attitude toward oneself. *Self and Identity*, 2003; **2**: 1-12.
60. Breines JG, Chen S. Activating the inner caregiver: The role of support-giving schemas in increasing state self-compassion. *Journal of Experimental Social Psychology*, 2013; **49**: 58-64.
61. Wilkinson RG, Pickett K. *The Spirit Level: Why Equality is Better for Everyone*. Rev ed. London: Penguin, 2010.
62. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, 1983; **67**: 361-370.
63. Wakefield JRH, Bickley S, Sani F. The effects of identification with a support group on the mental health of people with multiple sclerosis. *Journal of Psychosomatic Research*, 2013; **74**: 420-426.
64. Tennant R, Hiller L, Fishwick R, Platt S, Joseph S, Weich S, et al. The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes*, 2007; **27**: 63.
65. Stewart-Brown S, Janmohamed K. *Warwick-Edinburgh Mental Well-Being Scale. User Guide. Version 1*. Warwick: Warwick Medical School, University of Warwick, 2008.
66. Cleary M, Freeman A, Walter G. Carer participation in mental health service delivery. *International Journal of Mental Health Nursing*, 2006; **15**: 189-194.

67. Rose LE, Mallinson RK, Walton-Moss B. Barriers to family care in psychiatric settings. *Journal of Nursing Scholarship*, 2004; **36**: 39-47.
68. Wiley. *Health Expectations - Author Guidelines*. 2015. [cited 2015 Apr 13]
Available from: [http://onlinelibrary.wiley.com/journal/10.1111/\(ISSN\)1369-7625/homepage/ForAuthors.html](http://onlinelibrary.wiley.com/journal/10.1111/(ISSN)1369-7625/homepage/ForAuthors.html).

Appendices

Appendix A: Independent Peer Review Approval



Faculty of Health Sciences

INDEPENDENT PEER REVIEW APPROVAL FEEDBACK

Researcher Name Sophie Neech
Title of Study Experiences of Service User Involvement in Mental Health Settings
Award Pathway DClinPsy
Status of approval: **Approved**

Action now needed:

You must now apply to the Local Research Ethics Committee (which serves the Trust within which you intend to complete your study) for approval to conduct your study. You must not commence the study without this second approval. To seek approval you will need to complete the application form for the committee and forward copies of your proposal.

Please forward a copy of the letter you receive from the L.R.E.C. to Helen Sutton at Blackheath Lane as soon as possible after you have received approval. Once you have received L.R.E.C. approval you can commence the implementation phase of your study. You should note that any divergence from the approved procedures and research method will invalidate any insurance and liability cover from the University. You should, therefore, notify the Panel of any significant divergence from this approved proposal.

It is now possible to begin writing your dissertation and you may wish to consult with your supervisor on this matter.

Comments for your consideration:

Thank you for forwarding the amendments requested by the Independent Peer Review Panel (IPR)

A handwritten signature in blue ink, appearing to read 'E Boath'.

Signed: Dr E Boath *Chair FHS Ethics Panel*
Chair of the Faculty of Health Sciences IPR Panel

Date: 05 February 2014



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Date: 05 February 2014

To whom it may concern

Application for Independent Peer Review Approval

Researcher: Sophie Neech

Study Title: Experiences of Service User Involvement in Mental Health Settings

I can confirm that Staffordshire University supports this research project proposal being put forward by the above research project applicant, and that the University is willing to act as sponsor of the project if it received LREC approval.

Our support for this project takes account of the outcome of an independent peer review of its scientific merit undertaking within the University.

I can also confirm that the University has generic indemnity/insurance arrangements in place as stated on the attachment to this letter, that arrangements will be in place before the study starts for the research team to access resources and support to deliver the research as proposed, that arrangements to allocate responsibilities for the management, monitoring and reporting of the research will be in place before the research starts and that the duties of sponsors set out in the NHS Research Governance Framework for Health and Social Care will be undertaken in relation to this research.

Professor Nachi Chockalingam
Chair,
University Academic Ethics Sub-Committee



Appendix B: Research Ethics Committee Approval



Telephone: 0115 8839425.

15 May 2014

Ms Sophie Neech
Trainee Clinical Psychologist
Staffordshire University
Science Centre, Leek Road
Stoke-on-Trent
ST4 2DF

Dear Ms Neech,

Study title:	Experiences of Service User Involvement in Mental Health Settings
REC reference:	14/EM/0159
Protocol number:	N/A
IRAS project ID:	131861

Thank you for your letter of 15th May 2014. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 09 May 2014

Documents received

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		15 May 2014
Participant Consent Form	2	12 May 2014
Participant Information Sheet: Staff	2	12 May 2014
Participant Information Sheet: Service User Representative	2	12 May 2014

Approved documents

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter		31 March 2014
Covering Letter		15 May 2014
Evidence of insurance or indemnity	Zurich Municipal for	16 July 2013

	Staffordshire University	
Interview Schedules/Topic Guides	Individual Interviews V1	03 March 2014
Interview Schedules/Topic Guides	Focus Group V1	03 March 2014
Investigator CV	Ms Sophie Neech	03 March 2014
Letter from Sponsor		05 February 2014
Other: Supervisor CV - Dr Alison Tweed		07 March 2014
Participant Consent Form	2	12 May 2014
Participant Information Sheet: Staff	2	12 May 2014
Participant Information Sheet: Service User Representative	2	12 May 2014
Protocol	1	03 March 2014
REC application	131861/588799/1/1 81	31 March 2014

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

14/EM/0159	Please quote this number on all correspondence
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Yours sincerely



Liza Selway
REC Manager

E-mail: NRESCommittee.EastMidlands-Nottingham2@nhs.net

Appendix C: Trust Research and Development Approval



Our Ref: AB/R264

29 May 2014

R&D Department

Ms Sophie Neech
Trainee Clinical Psychologist

Telephone: [REDACTED]

Dear Sophie

Study title: Experiences of Service User Involvement in Mental Health Settings

We have considered your application for access to patients and staff from within this Trust in connection with the above study.

On behalf of the Trust and the Responsible Care Professionals within the Psychology Directorate have now satisfied themselves that the requirements for Research Governance, both Nationally and Locally, have been met and are happy to give approval for this study to take place in the Trust, with the following provisos:

- That all researchers coming into the Trust have been issued with either a letter of access or honorary contract by ourselves
- That you conform to the requirements laid out in the letters from the REC dated 15 May 2014, which prohibits any changes to the agreed protocol
- That you keep the Trust informed about the progress of the project at 6 monthly intervals
- If at any time details relating to the research project or researcher change, the R&D department must be informed.

Your research has been entered into the Trust database and will appear on the Trust website.

As part of the Research Governance framework it is important that the Trust are notified as to the outcome of your research and as such we will request feedback once the research has finished along with details of dissemination of your findings. You will be asked to provide a copy of the final report and receive an invitation to present final feedback via our research seminar series. To aid dissemination of findings, copies of final reports are placed on our Trust Website. To this end, please contact me towards the completion of the project to discuss the dissemination of findings across the Trust and a possible implementation plan.

If I can help in any other way please do not hesitate to contact me.

Yours sincerely

R&D Manager



Our Ref: R264

2 June 2014

R&D Department

Telephone: 0

Ms Sophie Neech
Clinical Psychologist

Dear Sophie

Letter of access for research

This letter should be presented to each participating organisation before you commence your research at that site **Trust.**

In accepting this letter, each participating organisation confirms your right of access to conduct research through their organisation for the purpose and on the terms and conditions set out below. This right of access commences on **1 June 2014** and ends on **30 September 2015** unless terminated earlier in accordance with the clauses below.

As an existing NHS employee you do not require an additional honorary research contract with the participating organisation(s). The organisation(s) is/are satisfied that the research activities that you will undertake in the organisation(s) are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this organisation that the necessary pre-engagement checks are in place in accordance with the role you plan to carry out in the organisation(s). Evidence of checks should be available on request to **Trust.**

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving the organisation(s) permission to conduct the project.

You are considered to be a legal visitor to **Trust.**

L003 - Example NHS to NHS letter of access for NH researchers who have a substantive NHS contract of employment with the organisation or clinical academics with an honorary clinical contract with an NHS organisation

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premises. You are not entitled to any form of payment or access to other benefits provided by [redacted] Trust or this organisation to employees and this letter does not give rise to any other relationship between you and or this organisation, in particular that of an employee.

While undertaking research through [redacted] Trust you will remain accountable to your employer [redacted] NHS Trust but you are required to follow the reasonable instructions of your nominated manager [redacted] Trust in each organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by [redacted] Trust or this organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with [redacted] Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with [redacted] Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on [redacted] Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and each participating [Insert organisation] prior to commencing your research role at each site.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

The organisation(s) will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if

L003 - Example NHS to NHS letter of access for NH researchers who have a substantive NHS contract of employment with the organisation or clinical academics with an honorary clinical contract with an NHS organisation
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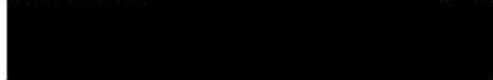
challenged. Please note that the organisation(s) accept no responsibility for damage to or loss of personal property.

This letter may be revoked and your right to attend the organisation(s) terminated at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of the organisation(s) or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the organisation that employs you through its normal procedures. You must also inform the nominated manager in each participating organisation.

Yours sincerely



R&D Manager

cc:



Appendix D: Participant Information Sheet

Participant Information Sheet Experiences of Service User Involvement

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. **One of our team will go through the information sheet with you and answer any questions you have.** This should take about 10 minutes. Please ask us if there is anything that you are not clear about.

Part 1 tells you the purpose of this study and what will happen if you take part.

Part 2 gives you more detailed information about the conduct of the study.

This study aims to understand peoples' experiences as service user representatives in mental health services. We want to know why people decide to be a representative, what they expect, their experiences and what they get out of it. We also want to know if you have any recommendations to improve service user involvement.

You have been invited to take part as you have been identified as a service user representative. It is your decision as to whether or not you choose to take part in the study. Before you make your decision we will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

Part 1

What will happen if I take part?

You will be asked to attend a research interview, at [REDACTED], or another convenient location. This will last a maximum of an hour and a half. We will talk to you about your role as a mental health service user representative.

Everyone who takes part in the study (about 10-15 people) will then be asked to attend a discussion group at [REDACTED]. We will present to the group the findings of the study and ask for your thoughts. We will also work together as a group, along with two staff members responsible for service user involvement from [REDACTED] Trust, to come up with some recommendations for service user involvement within mental health services. This group discussion will last about two hours.

What will I have to do?

You will be asked to attend the research interview and discussion group.

In order to take part in the study you must:

- Be over the age of 18
- Be able to communicate fully in English (within the constraints of the project interpretation is not possible)
- Be a current or past user of mental health services
- Be a current or past service representative within [REDACTED] Trust
- Have taken part in at least one activity/form of service user involvement (e.g. staff interview panel)

What are the benefits of taking part?

We cannot promise the study will help you, but the information we get from this study will help to develop service user involvement within mental health services.

What are the disadvantages of taking part?

Talking about previous experiences within mental health services may be difficult for some people. Any complaint about the way you have been dealt with during the study or any possible difficulties you might suffer will be addressed. The detailed information on this is given in *Part 2*.

Will my taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. The details are included in *Part 2*.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2

What will happen if I don't want to carry on with the study?

You can change your mind at any time without giving a reason. If you decide you do not want to be part of the study, let one of the research team listed at the end of this information sheet know. If you have already had your interview and then decide you want to withdraw from the study you must let us know before the research is published. If this happens, all information relating to the interview will be destroyed. This will not affect your current or future treatment.

What if there is a problem?

After the interview has finished a debrief will be given, which includes asking you if the study has raised any concerns, and if you feel it is helpful we can give you more information about additional support. At this point we will also give you details of approximate time-scales for the rest of the project. The same will happen at the end of the focus group, when you will also be informed when the summary of findings will be available.

If you disclose information about someone's life being at risk then we have a legal obligation to tell someone else in order to safeguard, for example by contacting your GP, the police or social services, depending on the nature of the disclosure. If this were the case we would always try to discuss this with you first.

If you have a concern about any aspect of this study you should ask to speak to Sophie Neech or Alison Tweed who will do their best to answer your questions (contact details at the end of this document). If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS) [REDACTED]

What happens to my information?

All information that is collected about you during the course of the research will be kept strictly confidential. The research interview and discussion group will be audio recorded. The audio recording will be written up, and what you say will be made anonymous. We will change your name and any specific information that may identify you to others. The information will be stored on a secure encrypted storage

device and kept in a secure locked space at Staffordshire University for 5 years, after which it will be destroyed.

What will happen to the results of the study?

We will be feeding back the results of the study in the discussion group. At a later date a summary of the findings will be available via the researchers (contact details at the end of the document).

Will I get paid to take part?

We cannot pay you for your time during the research. However, we will be able to reimburse you for your travel expenses to and from the interview and focus group.

Who is involved in the research?

This study is being done by Staffordshire University, Keele University and [REDACTED] Trust.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Nottingham (2) NHS Research Ethics Committee and the Faculty of Health Sciences Independent Peer Review panel at Staffordshire University.

Contacting the Researchers

You can contact the researchers on the details below:

Sophie Neech
Principal Investigator
n027407b@student.staffs.ac.uk
01782 294 007

Alison Tweed
Research Supervisor
a.tweed@staffs.ac.uk
01782 294 007

If you decide to take part in the study you will be given a copy of this Participant Information Sheet and a signed consent form to keep.

Appendix E: Participant Reply Sheet

Staffordshire & Keele Universities
Doctorate in Clinical Psychology
DClinPsy
Faculty of Health Sciences, Staffordshire University,
Leek Road, Stoke-on-Trent ST4 2DF
E n027407b@student.staffs.ac.uk

T +44 (0)1782 - 294007
W <http://www.staffs.ac.uk>



Keele University

Experiences of Service User Involvement in Mental Health Settings

Are you interested in taking part in a face-to-face interview about being a service user representative? Whether you are new to involvement, or have been doing it for years, we want to hear about your experience!

We want to interview people who have been service users and representatives within [REDACTED] Trust. We can travel to you for the interview, which will last about an hour. Alternatively we can reimburse your travel expenses. We are also hoping some people interviewed will attend a focus group in [REDACTED] later in the year.

Please leave your contact details below, and post this form back in the envelope provided. One of the researchers will contact you to answer any questions you may have and to arrange an interview.

Name:

Contact telephone number:

Email address:

Address:

In the meantime, please feel free to take a copy of the Participant Information Sheet to read through. One of the researchers will go through this again with you before starting the research.

Appendix F: Consent Form

Participant Identification Number:

CONSENT FORM

Title of Project: Experiences of Service User Involvement

Name of Researcher: Sophie Neech

Please initial all boxes

1. I confirm that I have read and understand the information sheet dated 12/05/14 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. My medical care and legal rights will not be affected. ☐
3. I consent to the use of audio recording, and understand that what I say may be quoted verbatim. ☐
4. I agree to take part in the above study ☐

_____	_____	_____
Name of participant	Date	Signature

_____	_____	_____
Name of person taking consent	Date	Signature

Appendix G: Interview Guides

Interview Guide (Version 1)

Interview preamble:

- Explain the purpose of the project and how results will be used.
- Seek consent to audio record.

Audio recorder on.

- Discuss anonymity
- Confidentiality (apart from if harm to self/others mentioned)
- Reaffirm right to withdraw
- Any questions?

Explain interview structure:

- Will cover experience of being a service user representative
- Reasons for starting the role
- Personal outcomes/achievements
- What has been good/difficult
- What can be done differently
- Anything else to add

- Can stop recording
- Take break

1. Service user involvement history

In your own words, could you tell me about your experience of being a service user representative?

Service user involvement – types of activities, meetings, policy, how frequently, duration in role?

2. Motivations

Could you tell me how you found out about service user involvement?
Why did you decide to get involved?

*Awareness of service user involvement at a local level/wider scale,
mental health staff as advocates, promotion from groups/bodies?
Explore point in treatment; still a service user? Why at this point?*

3. Outcomes

What do you get out of service user involvement?

What is enjoyable? What difference has it made? Is it part of a plan?

Receive acknowledgement?

4. Strengths and challenges

What has been difficult within the role as service user representative?

What has been positive?

Personal level/group/local/national/international? Facing any common issues?

5. Recommendations

What would you recommend doing differently in regards to service user involvement?

Why? What is working well/not so well? Small/larger scale?

6. Final thoughts

Is there anything else about your own experiences of being a service user representative, or service user involvement in general, that you would like to add?

Audio recorder off.

- Thank you.
- Reminder of date and time of focus group.

Interview Guide (Version 2 - 19/10/14)

- Discuss anonymity; Confidentiality; Reaffirm right to withdraw; Can stop recording; Take break
 - Any questions?
 - Will cover experience of being a service user representative; Reasons for starting the role; Personal outcomes/achievements; What has been good/difficult; What can be done differently; Themes from initial coding/analysis; Anything else to add
- 1. In your own words, could you tell me about your experience of being a service user representative?**
Service user involvement – types of activities, meetings, policy, how frequently, duration in role?
 - 2. Could you tell me how you found out about service user involvement? Why did you decide to get involved?**
Awareness of service user involvement at a local level/wider scale, mental health staff as advocates, promotion from groups/bodies?
Explore point in treatment; still a service user? Why at this point?
With the exception of lived experience, what do you think you bring to your involvement role?
What do you hope to get from it?
 - 3. What do you get out of service user involvement?**
What is enjoyable? Receive acknowledgement?
Can you give an example of when your contribution has made a difference? How did this make you feel?
Is it part of a plan? Wanting to work in mental health? WHY?
 - 4. What has been difficult within the role as service user representative? What has been positive?**
Personal level/group/local/national/international? Facing common issues?
How might your experiences of mental health services help you in involvement? How might your experiences hinder you?
 - 5. What would you recommend doing differently in regards to service user involvement?**
Why? What is working well/not so well? Small/larger scale?
 - 6. Analysis**
Some people say that they like the ‘insider perspective’ that they get from being a service user representative. Is this true for you? Why?
 - 7. Is there anything else about your own experiences of being a service user representative, or service user involvement in general, that you would like to add?**

Thank you. Invite to focus group.

Interview Guide (Version 3 - 12/12/14)

- Discuss anonymity; Confidentiality; Reaffirm right to withdraw; Can stop recording; Take break
- Any questions?
- Will cover experience of being a service user representative; the reasons for starting the role; the sense of feeling valued from involvement activities; What the impact might be on future service users; the impact on individual wellbeing; future plans; anything else to add

1. In your own words, could you tell me about your experience of being a service user representative?

Service user involvement – types of activities, meetings, policy, how frequently, duration in role? Free choice? Some degree of therapeutic change?

2. Could you tell me why did you decided to get involved?

Giving back?

Analysis – show framework

3. Do you feel you are valued as a service user representative?

How do you know?

How do staff contribute to this?

4. What difference do you think your involvement activities make in the lives of future service users?

Can you give an example of when your contribution has made a difference?

How did this make you feel?

5. How do you think involvement impacts your own wellbeing?

How do you feel after taking part in involvement activities?

What is the impact the following day(s)?

6. Where do you see yourself in the future, in relation to your role?

Why?

When/why would you stop being a service user representative?

7. What would you recommend doing differently in regards to service user involvement?

Would you want involvement to become more structured within the Trust?

8. Is there anything else about your own experiences of being a service user representative, or service user involvement in general, that you would like to add?

Thank you. Invite to focus group.

Appendix H: Participant Support Sheet

Experiences of Service User Involvement in Mental Health Settings

Thank you for taking part in the study.

If you have a concern about any aspect of this study you can ask to speak to the following people who will do their best to respond to your questions or concerns:

- Sophie Neech, Principal Investigator 01782 294 007
n027407b@student.staffs.ac.uk
- Alison Tweed, Research Supervisor 01782 294 007
A.Tweed@staffs.ac.uk

If you remain unhappy and wish to complain formally, you can do this via the NHS Complaints Procedure. Details can be obtained from the Patient Advice and Liaison Service (PALS) [REDACTED].

If you feel you need additional support since taking part in the study you can contact the following services:

- Your GP or other health care professionals you may currently be working with.
- Samaritans: <http://www.samaritans.org>, 08457 90 90 90 (24 hours).
- Mental health charity MIND: <http://www.mind.org.uk>, 0300 123 3393.

Appendix I: Examples of Grounded Theory Coding

Legend

(p) – pause

(pause) – long pause

CAPITALS – emphasis

Participant 2		
<i>Feeling valued</i>		
<i>Staff control opportunities</i>		
<i>Transitions</i>		
<i>Wellness</i>	69	little interview, and um in the end/ I think they'd only
<i>Already an established agenda?</i>	70	wanted one or two, but/ because we were all so
	71	enthusiastic/ they agreed to make room for all of us/ Um
<i>Allocation to involvement activities</i>	72	(p) so I was invited to the research and development (p)
	73	um committee meetings/ and, another person was invited
<i>Control/ power</i>	74	to service user and carer ones/ It was originally going to
	75	be both, um, but that was fine/ I ACTUALLY um, wanted
<i>Payment</i>	76	to go to both/ but, they were very mindful that they only
	77	had the funding to pay us a session fee for one, and they
<i>Empowerment/ disempowerment</i>	78	didn't kind of want to exploit me/ But I, my argument was,
	79	but/ actually want to be PART of it/ (laughs) and that I
	80	don't mind about the money/ so, yeah I think there should
<i>Feelings of belonging</i>	81	be a bit more choice there perhaps/ But, they were [dis]
	82	absolutely lovely and they helped me settle in/ Before the
	83	first meeting they said um (p) you know (p) there's a lot of
<i>Jargon/ cultural obstacles (systems)</i>	84	sort of jargon and you know sort of abbreviations/ and
	85	were just used to the them/ so you can stop us at any
	86	point and don't worry about it eh/ and I was made to feel
<i>Us + them</i>	87	really comfortable um/ Have I gone past the first question?
	88	(laughs)
	89	I: No, no that's fine. Um So it sounds like a lot came from
	90	that first meeting there.
	91	Ptp: Yeah, its like they really (p)/ they do have their radar
<i>Staff with interest in involvement</i>	92	on you know/ and they do really seem to go out their way
	93	to help people/ (p) I mean she didn't have to do that/ Um

wellness	feeling valued	Participant 7
Transitions		
future service user experiences		
Staff Control opportunities		
narrowing the 'us + mem'	94 to use. Um, I had meetings with like the managers of the	meetings with staff
Belonging	95 whole hospital/ and stuff. So that kind of got my	feeling involved
Redistribution of power	96 confidence up/ and I enjoyed it when I was there/ So	Enjoying time,
changing service user experience	97 when I heard about the meetings down here I thought it'd	during inpatient stay
insider insight	98 be really good/ if... 'cause yeah, it does fill my time/ um (p)	Hearing about local involvement
Meaningful activity.	99 but it's NOT, I wouldn't just go to fill my time, I do enjoy it/	Having something to do.
staying well.	100 /Hearing, hearing about what's happening/ and, I like	needing to enjoy activity also.
challenging problems within the service	101 * having my own say when things aren't that good/ (p) It is	Hearing news
making a difference.	102 more than just filling my time (p)/	Speaking out
multiple gains.	103 I: What was your role in [city], with the redesign of the	Gaining many benefits.
Power/ Control (staff)	104 room?	
Differing agendas	105 Ptp: Um/ I don't know how I actually, how they let me do it	feeling unique?
Recovery (part of this)	106 in the end (laughs)/ Um, it was just a really old room, and	Trying to understand why this was helpful/ what staff understood this to be
Changing services	107 * it needed redoing (pause)/ I did have groups ALL the	
	108 time on that ward/ um, but I can't just... some people can	Knowing self - staying on path to recovery.
	109 just do therapy, and that's it, but I can't, I have to have	Being distracted
	110 something else to think about/ I couldn't just spend a	Feelings of accomplishment.
	111 year, just, in constant therapy/ it's like the other stuff was	Feeling welcome
	112 kind of like a distraction/ But it was really good. I go	
	113 back there now, and visit people/ It's (really good?)	
	114 I: So you came back here, and then did you seek out... oh	
	115 you said you heard about it via [organisation] -	
	116 Ptp: Yeah, when/ I come back I started going back to the	finding out from other service users.
	117 café, and then they told me about it there./	

In the above excerpts interviews have been transcribed following guidance for qualitative research.⁴⁶ Open coding is in the right margin, focused coding in the left, and the coloured codes refer to categories.⁴¹

Appendix J: Example of Grounded Theory Memos

Feeling Valued

10/11/14

Participants communicate a strong sense of feeling valued in the activities they are involved with as representatives. Value comes from within, from staff, service users and fellow representatives. Value has links with feeling confident, and a greater sense of self-esteem, which enables and promotes moving forward.

The sense of feeling valued is a strong theme within the interviews, with a number of different layers. To some the very fact that service user involvement exists is a symbol of value of lived experience in itself. Yet, there is more than valuing the experience, as service user representatives start to value themselves, and the other skills and qualities they bring to the role. Payment for involvement activities is frequently mentioned in relation to value, where although participants hold differing beliefs about whether or not they should receive payment for their contributions, they all attribute the concept of payment with that of value and respect for the service user representative.

The value of lived experience is key, where service user representatives recognise that their experience can make a difference to others. In order to engage in service user involvement individuals must first place value on their experiences, and what they can bring to the role.

Staff recognise the value of lived experience, and this is mentioned in relation to staff interviews, where users are asked to contribute to the recruitment process, considering candidates from the perspective of if they were to work with the representative:

So the service user's perspective, it's the values that person has, their behaviour, the way they, uh, they handle themselves. Are they

particularly nervous or jittery? Is that the sort of person you feel can aid your recovery? (Participant 4, 655-659)

Sometimes participants recognise that the process of attributing value comes from staff first, where they are told their story is important for others to hear, and something that staff alone are unable to provide:

I feel, and I'm told, that I'm an expert in my own health, the fact that I can give something back and KNOW what I'm talking about.

(Participant 8, 117-119)

The professionals do an AMAZING job. But who has better insight than people who've got lived experience? (Participant 8, 410-412)

The majority of participants saw payment for involvement roles as a sign of value, although some did not agree that service user representatives should take the payment, especially when they were also receiving benefits. The value of payment for many bridges the gap between service user and staff, again linking with the identity shift that appears to occur within this role.

I get paid, a salary (laughs), which is good...that definitely shows you're being valued, because (hesitant) the NHS don't really wanna give out their money. So that's good. (Participant 3, 326-330)

It's a twenty-pound fee you get, on top of your expenses. And I think when I first went in to service user participation, it felt wrong because (p) it was just the right thing to do, to give my opinion. I didn't want to be paid for it, I WANTED to do it of my own free will, and it was the right thing to do. But now I see it that I'm valued. I don't do it for the money, and there's lots of volunteering I've done where you don't get paid. But when you do get paid it makes you feel like they really value what you're doing. And it's a token of value, not a token of money. Um, (p) (and?) I think it makes people...I've spoken to other service users, and they said it makes them feel valued. It's not a case of 'well, we have to fill the numbers, we have to tick the box to get a service user'. It's a case of 'well we're gonna have to pay somebody. We want

their views', and it sort of legitimises it all. And it does make you feel quite valued. (Participant 8, 172-188)

For some user representatives, there may have been more apprehension around the value of involvement, especially in relation to individual staff members (and during the interviews there was still some fear of tokenism within involvement activities), but as time went on and more activities were undertaken the value that may have been questioned began to emerge:

Um, but yeah I really did feel that I was encouraged to take part and as the meetings went on I gradually got to learn more and more about it and, um I felt completely welcomed and like my opinion was valid. (Participant 2, 99-102)

They literally told me they had a blank piece of paper you know they'd got this idea and they'd got the, you know the time to do it but they (p) they wanted OUR input to actually shape the direction of it so it was REALLY EXCITING (Participant 2, 153-157)

One participant reflects on how it is not just the involvement, and value, at an individual level, but how staff value her enough to ask her to share her experience with others:

And I was thinking WOW, you know, people have faith in me, and they're gonna let me go and talk in front of all these people. (Participant 2, 198-200)

Even when individuals did not feel they could make a valuable contribution, staff appear to have been able to show service user representatives what involvement adds to the service, and means to them:

She was like 'you can do it'. And I think that's quite a lot of acknowledgment, that someone believes in your capabilities, even if you don't, all the time. (Participant 3, 344-346)

Another example of staff indicating the value they place on involvement and lived experience was highlighted in one interview where a service user representative had shadowed a Director in the Trust:

And he held a meeting, and I presume it's one of those big meetings where all the heads turn up. And I sat there, and uh, [name] said to this one guy 'right, tell me about so and so'. And he went 'um, it can wait 'til the next meeting, um'. [Name] said 'why?' And he said (whispers) 'because we've got a service user here'. [Name] said 'she is covered by CONFIDENTIALITY, same as EVERY ONE ELSE IS, you CARRY ON.' And I thought that was really good, to make that stand, to make me feel EQUAL. (Participant 5, 948-957)

Another participant goes on to explain how involvement proves your value as a service user, and that individuals can move forward, with their experience and empathy having an impact on others:

It's my passion. It's what I want to do. I've lived and breathed it. And the service user participation gives you that confidence that you CAN do it, and you're listened to. 'Cause they really do listen, and what you say really makes a difference. (Participant 8, 122-126)

The same participant reflects on attending a meeting with staff members, where she was one of the only service user representatives:

We all sat next to each other, which was NICE. Everybody introduced themselves. And, I don't know whether this is right or wrong, but it felt right for ME, they were (p) TREATING me like a professional. They were saying 'well what do you think?', you know. 'You've lived this. Your opinion is very important'. (Participant 8, 156-162)

The perceived value of lived experience seems to create an element of power for service user representatives, a sense of knowing more, or something different, to staff. Some mention that although qualifications are important, that there is a lot that cannot be learnt from theory and books.

The sense of feeling valued may also be a way to make sense, and meaning, from past experiences, which links to contributing to the experience of future service users.

Still need to know:

- What factors influence feeling valued?
- Do you have to have already undergone some form of therapeutic change?
- Do staff need to indicate this sense of value in order for it to be meaningful?

01/12/14

After meeting with my supervisor on 24/11/14 and deciding to focus more on the motivation/outcomes element of the study, it seems appropriate to move 'Seeing Impact' into the 'Feeling Valued' coding, as representatives report that actually seeing the difference they have made validates their efforts in relation to involvement (even those who do not enjoy the involvement activities).

Seeing Impact

17/11/14

Similar to the coding relating to Future Users Experiences, user representatives in the study report feeling their involvement was a success if they see a tangible link between their input and a change to individual or service provision. Tokenism provides the alternative perspective, where although they are asked for their views and contribution, it feels as though this is merely done to tick a box somewhere and not used in any meaningful way to inform future practice. Whereas user representatives understand that individuals may not change as a result of their intervention, they are more likely to want to see change as a result of their contribution to service development, for example.

There is a general sense of dissatisfaction that as a representative you are rarely informed of where your feedback has had an impact, or even if anything has been fed-back at another level:

She [staff member] wanted people to come along and film and talk about their, so I talked about my own personal experiences and so we created a video...I don't know how much of it was used. (Participant 1, 215-218)

I've been to some of them [user and carer forums] and I listen to what they talk about and some of the issues and stuff, and I know where that gets fed back to (p). And, and it doesn't necessarily make a difference (p). So I think the issue is with, sometimes you're all just like banging your head up against a brick wall. It's GREAT that they have the meetings, but it's like if it, if they're not been taken seriously, then what's the point? That's what I think about like the, that involvement needs to be TRULY valued, and that's what makes the difference between just ticking the box to say 'we do it'. But, yeah, does it actually make a difference? (Participant 3, 504-515)

Sometimes this appears to link to the bureaucracy of the organisation and not having the infrastructure in place to be able to action change as a result of involvement:

I felt I was going along there to give representation of service user and carer um operational concerns and issues that hadn't been addressed at perhaps the local level, and need to, to be pushed up there. Um, but of course there wasn't an infrastructure to enable that to happen. So it was a tokenistic gesture again as far as I was concerned. (Participant 4, 203-209)

The issues of tokenism appear to relate to staff individual understandings of service user involvement and their engagement with the process (see 'Staff Engagement' coding):

I sort of got lost. They weren't aware really of what my point of being there was. Which is a shame, because somebody somewhere must

have thought there was a point to me being there. (Participant 8, 307-310)

When user representatives do see the benefit of their work (which was reported in some cases), they appear more enthusiastic to continue with involvement, and get a greater sense of being valued.

01/12/14

Feedback from a user representative on 30/11/14 on coding:

'Seeing Impact' is really relevant. It's an issue that keeps coming up, as so often the results of involvement don't get back to those who participated.

Currently there's a working group as part of the subcommittee to look into support of those involved which should be addressing these kind of issues. This may have come up in some transcripts? It definitely taps into how the reps see the importance of their participation.

Seeing impact seems, therefore, to also link to staff controlling involvement opportunities.

- Are staff the only ones that can actually contribute to the feeling of being valued?

10/01/2015

The last two participants confirmed the theme of feeling valued. There were some exceptions to this, for example when no one had reported back the outcome of an interview day, however this was seen as the nature of working within a large organisation.

Appendix K: *Health Expectations* Author Guidelines⁶⁸

Health Expectations. An International Journal of Public Participation in Health Care and Health Policy

John Wiley & Sons Ltd

Edited By: Carolyn Chew-Graham Impact Factor: 2.852

ISI Journal Citation Reports © Ranking: 2013: 11/70 (Health Policy & Services); 18/86 (Health Care Sciences & Services); 30/162 (Public

Environmental & Occupational Health); Online ISSN: 1369-7625

Impact Factor: 2.852

General

Health Expectations publishes original material relating to all aspects of public participation in health care and health policy including:

- the involvement of patients and their advocates in decisions about individual health care;
- the involvement of health service users and their representatives in aspects of service design, delivery and evaluation;
- the involvement of health service users and family members in efforts to enhance the quality and safety of care;
- the involvement of wider publics in debates about health care policy.

The journal aims to be multidisciplinary and international in scope.

The following types of material will be published:

- Original research (including qualitative and quantitative work, primary studies and systematic reviews).
- Review Articles (including papers which clarify concepts or develop theories, and papers which critically assess developments and trends).
- Viewpoint Articles (well argued opinion pieces, and interviews with people who have made significant contributions to the fields of interest to the journal). These will normally be commissioned.

- Book reviews, and reviews of patient information materials and consumer health information systems. These will normally be commissioned.
- Original research, review and viewpoint articles will be peer reviewed by at least two independent referees.

Format

The typescript should be on A4 paper on one side only, double spaced with a wide margin on each side. Original Research Papers and Review Articles should usually not be longer than 5000 words. Viewpoint Articles will not normally exceed 2000 words, and reviews of books and information materials should be less than 1000 words long.

Structure

All manuscripts submitted for consideration as Original Research Papers, Review Articles or Viewpoint Articles should include: a title page, a structured abstract, keywords, main text, references and (if applicable) tables, and figure legends.

Abstract

The abstract should be on a separate page and should not exceed 250 words. The abstract should be structured. Suggested headings for abstracts of primary research are: background or context; objective; design; setting and participants; intervention or main variables studied; main outcome measures; results; discussion and conclusions.

Language

The editors are aware of the debates surrounding use of the terms 'patient', 'consumer', 'client', 'user', 'lay person' etc. In the absence of consensus about preferred terms, authors are encouraged to use whichever they consider to be most appropriate. A brief explanatory note may be included to clarify which population is being discussed where necessary.

References

The Journal follows the Vancouver style. References should be numbered sequentially as they occur in the text and identified in the main text by numbers in superscript after the punctuation. The reference list should be prepared on a separate sheet from the main text, and references should be listed numerically.

Paper 3: Commentary and Reflective Review

My Journey with Action Research

Word Count: 5792

Introduction to Action Research

This paper uses an action research framework to provide a reflective account and critique of the research undertaken. After introducing action research, I will describe my encounters with the approach, and consider how the literature review and grounded theory study (Paper 1 and 2) fit within an action-reflection cycle (Fig.1).¹

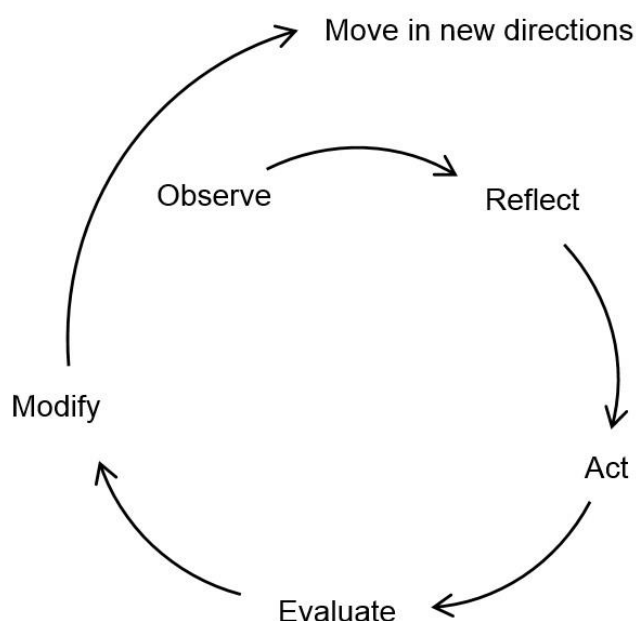


Figure 1 Action-Reflection Cycle

The cycle guides researchers to observe problems in current practice, reflect on the causes, identify and try possible solutions, monitor the outcomes, evaluate the process, and use this learning to modify practice.

Lewin, a scientific pragmatist, who in addition to attempting to explain phenomena focussed on practicalities of change, is credited with establishing action research in the 1930s². Lewin considered social science a means to address social justice and raise the self-esteem of minority groups, by working directly with people to support change.² Action research arises from a sense of dissatisfaction, where researchers take on the role of scholar/activist, seeing the potential for change.³ Working with disempowered populations, this methodology aims to address participant

concerns, and explore the cause of oppression.⁴ A process of research, education, and action should be present, whereby participants share their skills and knowledge to transform their situation.^{4,5} The approach can be practitioner-based, where one identifies gaps within their own practice, looking to action research to explore options and support improvement.¹ There are clear links to applied psychology⁵ and the role of the reflective practitioner.¹ By observing and reflecting on current psychological practice, psychologists are able to understand their own role and create effective change. The process for social change connects with community psychology, where understanding social context and relationships supports empowerment of communities through research and action.⁵

When I mentioned to Alison Tweed, my thesis supervisor, I would like my thesis to make a difference, she suggested action research. I arranged to meet Mary Brydon-Miller, a professor from Cincinnati on a professional exchange to support UK universities with action research. She told me about research that helped change individual lives, including Brinton Lykes'⁶ work with Guatemalan Mayan communities, Micarl Kral's⁷ youth suicide prevention study, and Sarah Hellmann's⁸ arts-based dissertation. There is no single methodology or formula to follow, and action research operates alongside other methodological approaches. Creative research techniques, such as PhotoVoice⁹ (photography and community action), are increasing in popularity. Despite action research's roots in academic research from the 1930s, some universities and departments still struggle with the process, especially the procedures and ethical approvals that do not follow the positivist scientific paradigm (where 'truths' are found by observing the world). In fact, Mary was in the UK to address the role of ethical approval committees regarding action research projects.¹⁰

We discussed American and British culture and history, and the impact social movements and individuals can have on cultural change. We had both studied at the University of California; Mary at Santa Cruz and myself at Berkeley, a liberal arts college known for its role in the free speech movement. We both identified addressing injustice and supporting change

as part of a researcher's responsibilities. I believe it is important to use my education and training in a meaningful way, supporting those experiencing difficulties, and empowering others.

I spent some time at the University of Cincinnati's Action Research Center meeting a number of researchers. Sarah Hellmann's work with homeless women in an inner-city shelter had the most impact on my understanding of action research. Sarah took me to her weekly art therapy workshop, where among the rows of single beds in the hostel dormitory, two large tables were set out with art materials. Sarah had brought music to the session, and asked residents if they would like to listen to it while using art to express their feelings. I engaged in the session, and listened to the women speak about their lives. There were stories of pain, distress, and sadness when the women explained their paintings at the end of the session. However, this was the first step in a process of helping them explore their current situation. The women experienced a shift in power, and their voices were being heard. Sarah's research would have a lasting impact not only for participants; it provided hope, insight, and empowerment to individuals in the local community. Her work also inspired me to pursue an action research project, acknowledging the benefit it could have to individuals participating in the study.

Observations

The first part of the action-reflection cycle is observation; asking how things are currently, and what needs changing.¹ I started clinical psychology training after working in substance misuse in the voluntary sector, where user involvement was fundamental to service development and delivery. Upon starting my NHS placements, I noticed how little was being done to hear and incorporate the user voice. There was, however, a team of user and carer consultants on the clinical psychology training course, who interviewed prospective trainees, attended subgroup meetings, and delivered some of the teaching.

I was helping greet prospective students one day when I met Gareth, a user

representative who had been helping with the course and an NHS Trust for a few years. We discussed involvement and where he felt there were gaps, especially in regards to clinical psychology. This was the first step to developing a research proposal relating to user involvement. The course staff put me in touch with other user and carer representatives, and we met to discuss their thoughts, particularly what would be useful for them to know about involvement and what needed addressing. They felt a degree of uncertainty around involvement; why it was present when at times it appeared undervalued, and why users and carers wanted to get involved.

Reflections

The next step was to think about why user involvement was important to users and the clinical psychology profession (the reflecting step of the action-reflection cycle). I believe user involvement transcends the profession, and is the responsibility of all staff within mental health services. Having recently read a special issue on user and carer involvement in the Division of Clinical Psychology's (DCP) publication,¹¹ I decided to email one of the authors, Emma Harding, who had written the article *User involvement: Why bother?*¹² Emma helped me explore ideas for research into user involvement, and shared with me recommendations arising from her thesis^{13,14} (including taking a grounded theory approach to future study of user involvement, with individual and focus group interviews to enable exploration of different perspectives and assumptions).

A small group of user and carer representatives from the D.Clin.Psy. course agreed to meet with me to think about the research. Initially, the plan was for them to act as 'consultants', where they would check the accessibility for users of key documents for the research, such as consent forms and interview schedules. The first consultation was around research questions, and three main questions to explore within the research were decided as a group:

- *Why do individuals become user representatives?*
- *What outcomes are achieved in the role of user representative?*

- *What can be done to improve mental health user involvement locally?*

Grounded theory seemed to fit well with the area of inquiry; little was known about the phenomena in question and the methodology facilitated a process of discovery.¹⁵ Unlike interpretative phenomenological analysis, thematic analysis, and other qualitative research methods, grounded theory detects socially-based processes, enabling construction of a conceptual framework or 'theory' from the data. The generalisable nature of grounded theory lends itself to the area of enquiry, where the hope was to conduct research to enable change in relation to user involvement, and thus was broader than individual level enquiry. To achieve an element of generalisability within qualitative research, an appropriate approach had to be taken to incorporate this element prior to the writing up of results,¹⁶ hence the use of grounded theory. Grounded theory seemed to have clinical utility, where if the research could establish what was happening and why, in relation to user motivations for involvement, then mental health professionals would be better placed to facilitate the change towards meaningful user involvement.

Epistemologically speaking, I felt most aligned with constructivist grounded theory, where knowledge and truth are considered based on an individual's perspective and experience.¹⁷ I saw user involvement as a fluid concept, where participants (and researchers) would generate ideas and understanding through the process of research, and categories and themes would be constructed through my interaction with the data.^{15,18}

Action research mirrors the grounded theory approach in a number of ways. Knowledge and understanding in both approaches take shape progressively. Within action research, understanding develops as the nature and impact of action are understood, and participants and stakeholders converge towards a richer account of what has been attempted, accomplished, and learned.¹⁹ Both approaches can be used flexibly and responsively, constructing theory from experience.²⁰ Action research follows a similar ethos to constructivist grounded theory,¹⁸ acknowledging the researchers' and participants' roles and influences within the research and generation of knowledge. Action

research promotes community and organisational changes, but also creates personal changes in the action researcher, who may change their practice based on new knowledge and action. One aim of the doctoral thesis was for me to grow as a clinical psychologist. By using a research technique that explored experiences of users and supported reflective practice, I felt I would become a more insightful and reflective practitioner.

Incorporating user involvement in the research project was important to me, and within the small team of users and carers I had initially consulted with, two were keen to support the research in a more formal way. We established a research team; myself, two user representatives (Karen and Gareth), and my supervisors. User involvement is recommended within research,²¹ and as part of NHS research governance and ethical considerations, researchers are asked how users have been involved in research. It was difficult to know how much users could be involved in the project, as it had to be my own work to constitute being part of the D.Clin.Psy. assessment. Therefore, we agreed on the two representatives supporting the development of a proposal, recruitment, and some peer analysis, with the possibility of writing a summary of the research for users at a later date. Together we set about designing the project, and considered action research as a format to enable change. Although we wanted the research findings, or grounded theory, to be generalisable, it was also important for us to play a part in facilitating positive change locally.

Harding^{13,14} suggested focus groups as a means of grounded theory data collection, and the research team adapted this idea to feedback findings to participants. Within an action research context, it was important to involve participants in understanding the current state of user involvement, then work together to find solutions to some of the problems experienced. We incorporated the idea of improvement and change into the grounded theory elements of the research by asking participants within individual interviews how they thought user involvement could be improved locally. By inviting key staff members (responsible for user involvement) to the focus group, the

research became collaborative in nature, building links between practitioner and researcher roles¹⁹, and suggestions were more likely to be enacted.

I spoke to staff members in the local Trust who were keen to support the research. They suggested the findings could feed into development of a new user involvement strategy that was being written. The Trust was particularly keen to support the user involvement elements of the research, and told me about possible funding to pay user representatives for their time. We were successful with a funding application, making it possible to reimburse all user representatives and participants for their travel expenses, and to pay the two representatives on the research team a sessional fee; good practice in a national mental health research context.^{21,22}

Traditionally, when using grounded theory, a literature review would be undertaken only once research has been conducted. This allows findings to be grounded in the data and not influenced by other sources.²³ However, within the confines of this thesis, it was not possible to consider previous literature only upon completion of data collection. Furthermore, it is now recognised that researchers' preconceptions regarding research topics cannot be put aside easily during the research process.²⁴ This is considered counterintuitive as researchers study their areas of interest, tending to have prior knowledge of the topic.²⁵ A literature review helped me think of what was already known about user involvement. There appeared to be little research exploring user representative perspectives of involvement, understanding why users choose to get involved in representative activities, and what they gain from this.

The reflective process in the action-reflection cycle includes ethical considerations. As a research team we explored ethical implications, and I consulted NHS guidance regarding research governance and good clinical practice,^{26,27} and BPS research ethical guidelines.^{28,29} It was acknowledged that some individuals may find it difficult to speak about previous experiences, especially when recalling personal involvement with mental health services. Information regarding further support was therefore made

available to participants. There was also recognition that participants might disclose risk issues during the research process. If that occurred, I may have needed to break confidentiality for safeguarding and risk reasons, and this was explained to participants prior to interview and again at the focus group.

Ethical issues were also considered in relation to user and staff participants in focus group discussions together. User representatives suggested that user participants might feel uncomfortable talking about their experiences with staff members present. Therefore, members of staff only attended the latter half of the focus group, where data was used to develop an action plan and suggestions for future user involvement activities. A findings report was given to staff participants in preparation for the focus group (Appendix A), to ensure they were informed of the research findings. At the beginning of the focus group I made all participants aware of confidentiality, and that what was said would not affect treatment within the Trust. This was to be a time-limited study, and for ethical reasons no user participants would be contacted after the focus group had ended, other than to share the summary sheet.

Taking an action research approach and involving users in the doctoral research project was not without challenges. At independent peer review (IPR) stage within the university there were conflicting views between clinicians, users, and academics. For example, users representatives felt that if audio recording of the interviews was mentioned too early in the participant information sheet it would unnecessarily raise anxiety levels of potential participants. Therefore, while highlighting the aims and nature of the interviews we decided to explain the study first, and mention the recording element later in the information sheet. However, feedback from the IPR panel was that this was not clear for users, and thus the research team needed to clarify and explain the justifications behind our decision.

Action

Once ethical approvals were granted, we started recruitment. The user representatives on the research team were keen to assist with this, and were able to use their connections to inform potential participants about the research. They also provided links to staff members within the Trust, who promoted the study via formal networks. User representatives were keen to be involved, and I quickly started to receive contact details of potential participants. These individuals had already taken up roles as user representatives, and were generally eager for their voice to be heard in different forums, including research. Some participants mentioned how important it was to be asked to be part of a research study, and to see that clinicians were taking involvement seriously. I had an enthusiastic group of participants, and started to book interviews, eager to get started myself. However, grounded theory is a thorough process, where data collection and analysis are on-going throughout research. I wanted to progress with data collection, with a number of interviews booked in close together, but found that I had not given myself enough time to go through the process of open and focused coding before starting the next interview. Thus, the first few interviews may have suffered from a lack of engagement with the process of theoretical sampling and inductive technique.

After speaking to the user representatives on the research team, we felt participants would prefer to have their interview date put back slightly, than to end up with more superficial data. I contacted some of the participants, explained the interest in the study and that the process was gradual in order to get the most out of the interviews, and would they mind rescheduling for a later date. This proved to be helpful, and as a result I had more time to thoroughly analyse and reflect on each interview as it took place, staying closer to constructivist grounded theory.¹⁷

To ensure I was open to the data whilst coding, some peer coding took place,³⁰ and I attended a group with other trainee clinical psychologists using constructivist grounded theory, where we cross-coded small sections of transcripts. Early in the process, the user representatives in the research

team indicated their interest in supporting the coding procedure. Alison, my thesis supervisor, suggested holding a grounded theory workshop for the two representatives and myself. On the day of the workshop one of the user representatives was unwell and unable to attend, and so we audio recorded the session and sent the file across to ensure they were still included in the process. In order to maintain anonymity and confidentiality, user representatives on the research team were given small non-identifiable excerpts to code, and we met to discuss coding and ideas.

As well as the grounded theory coding, I also identified participant suggestions regarding how user involvement could be improved on a local level. Suggestions were organised into themes, and presented to participants, forming the basis of the focus group discussion (Appendix B). Five interview participants attended the focus group, with two members of staff attending the second part. I described the findings of the study, and participants had space to reflect. Then, after a break, we invited the two staff members into the room, and presented suggestions from the interviews on improving involvement locally. Topics were presented via a slide show presentation, and the group discussed each topic. Often these discussions were around the practicalities of suggestions. Sometimes the suggestions were met with surprise; for example, staff in the group were unaware that user representatives were not being adequately supported when they volunteered for staff recruitment days. During the focus group, user representatives and staff explored and agreed a number of actions. For each improvement topic, notes were taken on flip chart paper, which were later typed up (Appendix C) and sent to all individuals who attended the group.

Prior to the focus group, there were some concerns among the research team that the group might be used by participants as a forum in which to complain to staff about involvement difficulties. We were keen for the space to be used to explore difficulties, but with an action focus, and thus a plan was developed to introduce the aim of the group at the start,³¹ where we would promote open and respectful conversation, and make sure people felt

comfortable (Appendix D). During the group, there were some narratives around dissatisfaction of involvement practices, yet an honest dialogue ensued in which user representatives and staff spoke out about barriers they faced, and started a dialogue to work towards more meaningful involvement. Having two user representatives on the research team, who were advocates for the improvement of involvement within the Trust, meant the link between the research and practical implementation of suggestions from the interview and focus group data was more likely to happen.

Evaluation

Along with my own reflections on evaluating the project, I have attempted to capture the feedback and reflections of participants and the user representatives on the research team.

Participants spoke about how the research enabled them to feel valued and listened to, showing that their voice was important. They considered research a forum to understand perspectives, other than their own. This links to the grounded theory findings (Paper 2) where as user representatives are in transition, they become more open to consider other points of view. Participants said they learnt more about their situation from the research process, and some reflected that after hearing about the collective experience during the focus group, they would be more likely to challenge staff and the process if something was not working, and ask for support when needed. This empowerment appears to be an outcome from the action research element of the study, where change started to occur as a result of participants' understanding of their own situation. Participants commended clinical psychology for taking user involvement seriously, and perceived the study as important for the profession, as well as for individual users, staff, the academic institution, and the Trust. To participants, their involvement in research was ultimately seen as a form of user involvement, and a way to help improve services for others.

User representatives on the research team also spoke about the way their involvement in the study had gone beyond the standard level of involvement in a D.Clin.Psy. thesis. One representative recalled that before involvement in this project, the extent of their involvement in past trainee research had been completing a questionnaire, which had not felt particularly meaningful. Representatives felt their own involvement reassured participants the study was trustworthy and of value, and that lived experience of mental health difficulties brought a different perspective and richer results. Unexpected gaps presented themselves at times, for example, periods waiting for ethical approvals, and sometimes user representatives on the research team felt 'out of the loop'. However, they appreciated the flexibility and time taken to keep them up to date with developments, for example, recording the grounded theory workshop.

As user representatives were coding segments of transcripts, they felt they would provide an additional insight and perspective if they were interviewed as participants. The original ethical applications had not included this, and with the time constraints, we were unable to change the study at this point. However, by being on the research team, and hearing participant stories of involvement before being interviewed, the two user representatives would not have brought the same understanding of involvement. Their experience would be shaped by involvement in the study and reading transcript excerpts, making their experiences as a participant different to others.

Finally, the research team user representatives reflected they may not be representative of users participating in involvement activities; with both having had extensive experience with clinical psychology training, and speaking publicly about their experiences, whereas many user representatives would not be well enough to participate in research to the same extent. Due to being involved in the research project, the three of us were asked to speak to clinical psychology trainees about our experiences of working together, to encourage trainees to more fully involve users in research.

As a trainee, I found it challenging to get the right balance between meaningful involvement and completing my own work, which would be assessed as part of the D.Clin.Psy. Involving users in research takes time and resources, and at points I felt stretched; I knew I could work more quickly on the project by myself, but wanted to consult the research team. I believe user involvement provided valuable insight, as well as rigour and validation of data analysis. There were constraints within research systems, such as the IPR panel, yet I hope that in an action research sense our project has helped challenge some existing protocols, to enable more collaborative research to become established within the university.

Initially I found it difficult to not fall into my role as a clinician when working with the user representatives on the team, constantly checking they were feeling okay in relation to their involvement in the research process. I attended the Collaborative Action Research Network (CARN) annual conference, and heard staff in a mental health project recount similar difficulties in relation to the researcher-practitioner role.³² This reaffirmed the importance of being clear that during research my role was primarily that of a researcher. If the user representatives on the research team, or participants in the study, had been accessing psychological support with me, the research would have been different, perhaps less ethical, and power differentials would have needed greater consideration. This poses the question of whether collaborative action research at practitioner level within clinical psychology is more complex than it is in a classroom setting in education. Nevertheless, action research helped engage users within this study, initiated a number of changes to current practice, and will ultimately have a positive impact on future users of mental health services; a notion Gareth and I presented at the 2014 DCP annual conference.³³

Modification

Modification is the last section of the action-reflection cycle. If this were a pure action research project, it is likely there would be more than one cycle, as the change enacted from the research would be evaluated, and

modifications made, starting the whole cycle again. Although some elements of this research will continue beyond the 'action' mentioned in the previous section, we do not have the time or capacity to modify and act again in the same way. Therefore, instead of the modification, I will reflect on what I would suggest to others, and what I would do differently, if this research was repeated.

Participants were primarily recruited via existing user involvement networks within the local Trust. Many were similar in their educational levels, and most had been engaged with involvement for some time. Homogeneity of a sample is needed in grounded theory, to generate some kind of conceptual framework,¹⁷ yet the participants in this study may not have been representative of user representatives generally. Reaching saturation, whereby no new information can be gained from further data collection, is a challenge in a time-limited study, and some argue this can never be fully achieved.²⁴ Although theoretical sampling did occur in the study (where after coding data it is decided what still needs to be found in relation to a topic), and some level of saturation was found in relation to codes and categories, there may have been more to uncover (see Appendix E for grounded theory coding structure).

On reflection, I may have only given a voice to those user representatives linked to the dominant systems within the Trust, as I recruited participants via existing user networks and key members of staff. Anecdotally, I heard of users doing small pieces of involvement work, not linked to the user forums, and it appears their voice may be missing. As a staff member, I had a particular agenda in relation to this involvement activity, and sought participants using a system primarily governed by staff, linking to the conceptual framework in Paper 2. If I were to conduct this study again, I would spend more time reaching out to users in less formal representative roles, who may have encountered different experiences and motivations for their involvement activities, with the use of posters, leaflets, and recruitment via clinicians. There is also the possibility that because of staff governing involvement, users who would like to get involved are not given the

opportunity because they have not had contact with the appropriate staff member. Therefore, it may be useful to include those who are not representatives as participants. Only user representatives well enough to participate in involvement activities were interviewed, which again may have impacted representativeness, and although the inclusion criteria incorporated past user representatives, I did not have access to past representatives with the recruitment techniques. Thus, the experiences of those who left the representative role, and may have offered a different perspective, were possibly overlooked (although some participants reported leaving, and later coming back to involvement).

Reflecting on findings from the literature review (Paper 1), I wonder if this study has also contributed somewhat to disempowerment of front line staff. Invitations to the focus group went to user representatives participating in the grounded theory study, and two staff members responsible for the development of user involvement within the Trust. Clinical staff who implement and offer some of the involvement opportunities were excluded. It was an ethical decision to only invite two staff members, to allow participants to feel comfortable speaking honestly, yet we may have missed the clinician perspective.

Carer involvement often goes hand-in-hand with user involvement in mental health settings, yet this study looked solely at the experience and motivation of user representatives, rather than their carer counterparts. This was a decision made by the research team early on, where homogeneity of the sample was needed for a grounded theory study. One of the user representatives on the research team, who was also a carer, suggested that carers may have different motivations for starting involvement activities, and therefore carers were excluded from the study. There is also recognition by the research team that all participants were white British, yet participants spoke about wanting more diversity within involvement.

User involvement activities within the study should have been decided upon from the start, for example whether user representatives on the research

team could use their own experiences as part of the data, and these roles needed to be incorporated within ethical applications. The research team navigated involvement tasks as the study developed, however this often caused difficulties as we were unsure what was acceptable, for example in developing the research and analysing findings. In part, this may be due to little involvement existing in D.Clin.Psy. projects previously. Agreeing on expectations and involvement levels from the start would therefore be helpful, where involvement may take the form of consultation (users views are considered), contribution (users are research team members with some direct involvement in the research process), collaboration (active partnership), or control (user-researchers leading projects) within mental health research.²¹ With this decision made, a need to be flexible would still be required, as well as providing opportunities for research team support. At the CARN conference, mental health users involved in a collaborative research project described developing wellness plans for themselves and the research staff.³² This helped them recognise triggers and cope with difficulties that may arise during the research process.

By considering user involvement in this research in light of the conceptual framework presented in Paper 2 (Appendix F), it seems that user representatives in the research team may have had a similar experience to participants in the grounded theory study. As a staff member, I was somewhat in control of the research, and asked for user input at various points in the process. The representatives had to be well enough to meet and contribute; if one had become unwell for any period of time it is likely the research would have continued without them, due to the short time scales and deadlines for the project. This would have potentially had a negative impact upon the individual and meant that the study was less collaborative in nature. Both user representatives had been engaged in involvement activities for some time, and recognised their role in creating positive change for users, which links to the theme of making a difference to future users' experiences within the conceptual framework. There were also some transitions present within the research process, for example, as a result of involvement in this study, one user representative took on more of a

researcher involvement role within the Trust, applying their knowledge of grounded theory in different environments. Delivering a talk at the DCP conference may have acted as a transitional event, where a shift from being a user to expert may have been apparent, as the majority of conference delegates and speakers were mental health professionals.

New Directions

The research process has been interesting and enlightening, and I hope to be involved in research again during my professional career. As user representatives stated, it is a way to continually improve and develop, not only knowledge, but the future experience of users of mental health services. I will apply learning from this study to future research and clinical work. For example, within the grounded theory study (Paper 2) participants spoke about needing additional support and debrief a few days after involvement activities, once they had reflected on their involvement; a feature I can incorporate into any user involvement I am engaged with as a clinical psychologist.

Further exploration into how organisations can establish a culture of user involvement, and set up an appropriate infrastructure to incorporate the user perspective in a service development context, may be of value. A study of the difference between user groups and user representatives within an organisation would add to knowledge regarding the effectiveness of different forms and governance of user involvement. In addition, future research could explore user involvement links to the recovery model, increasingly common within mental health services. As mentioned in Papers 1 and 2, exploration of staff and user representative relationships and dynamics may support understanding of how hierarchies and power relations can be transcended to achieve meaningful user involvement. Clinicians' perceptions and experiences of user involvement also warrant further inquiry, to aid understanding into why some professionals refrain from incorporating involvement. Finally, further testing of the conceptual framework generated

in Paper 2 could be undertaken, using a quantitative methodology, to study the links between user involvement and wellbeing.

In the context of user involvement within the Trust and D.Clin.Psy. training, it is hoped that collaborative research will be more evident in the future. Users as equal partners in research, from the start of the process, may enable enactment of more meaningful and relevant research, perhaps supported by clinical psychology departments in academic settings. For example, users may identify research needs and present these to staff and trainees, in order for studies to be developed collaboratively from the very start of the research process.

Conclusion

This D.Clin.Psy. thesis has incorporated a grounded theory and action research approach to support understanding and change for user involvement in mental health organisations. As I embark on my career as a clinical psychologist, I feel optimistic I can take my learning and new experiences of participatory research into the field, and continue to develop with this new approach as part of my 'toolkit'. To be reflective scientist-practitioners I think there needs to be consideration as to how best to support those we work with; enabling voices to be heard, and empowering and supporting change, rather than purely observing and reporting findings. I heard Mary Brydon-Miller liken most research to bungee jumping,³⁴ where researchers dive in, grab the data they need, and get out of the setting as quickly as possible. I see research more as a collaborative process with those facing difficulties to find workable solutions, and supporting sustainable changes within local communities and mental health settings.

References

1. McNiff J, Whitehead J. *All You Need to Know about Action Research*. London: Sage, 2006.
2. Adelman C. Kurt Lewin and the origins of action research. *Educational Action Research*, 1993; **1**: 7-24.
3. Brydon-Miller M, Greenwood D, Maguire P. Why action research? *Action Research*, 2003; **1**: 9-28.
4. Hall BL. Participatory research, popular knowledge and power: a personal reflection. *Convergence: An International Journal of Adult Education*, 1981; **14**: 6-19.
5. Brydon-Miller M. Participatory action research: psychology and social change. *Journal of Social Issues*, 1997; **53**: 657-666.
6. Lykes MB, Sibley E. Exploring meaning-making with adolescents "left behind" by migration. *Educational Action Research*, 2013; **21**: 565-581.
7. Hong JS, Kral MJ, Sterzing PR. Pathways from bullying perpetration, victimization, and bully victimization to suicidality among school-aged youth: a review of the potential mediators and a call for further investigation. *Trauma Violence Abuse* [cited 2015 Mar 19]. Epub 2014. Available from: doi: 10.1177/1524838014537904
8. Hellmann S. *Growing up Hard: Understanding through Creative Expression the Resilience, Resistance, and Images of Relationships in the Lives of Three African American Adolescent Girls*. [PhD thesis]. Cincinnati: University of Cincinnati; 2011.
9. Chonody J, Ferman B, Amtrani-Welsh J, Martin T. Violence through the eyes of youth: a photovoice exploration. *Journal of Community Psychology*, 2013; **41**: 84-101.

10. Brydon-Miller M, Greenwood D, Eikeland O. Conclusion: Strategies for addressing ethical concerns in action research. *Action Research*, 2006; **4**: 129-131.
11. Chinn D, Davies S, Grant S, et al. (eds.) *Clinical Psychology Forum. 209. Special Issue: Service User and Carer Involvement*. Leicester: DCP, 2010.
12. Harding E. User involvement: why bother? Trainee clinical psychologist and/or service user? *Clinical Psychology Forum*, 2010; **209**: 42-45.
13. Harding E, Brown D, Hayward M, Pettinari CJ. Service user perceptions of involvement in developing NICE mental health guidelines: a grounded theory study. *Journal of Mental Health*, 2010; **19**: 249-257.
14. Harding E, Pettinari CJ, Brown D, Hayward M, Taylor C. Service user involvement in clinical guideline development and implementation: learning from mental health service users in the UK. *International Review of Psychiatry*, 2011; **23**: 352-357.
15. Harper D, Thompson AR. (eds.) *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*. Oxford: Wiley-Blackwell, 2012.
16. Mason J. *Qualitative Researching*. 2nd ed. London: Sage Publications, 2002.
17. Charmaz K. *Constructing Grounded Theory*. 2nd ed. London: Sage, 2013.
18. Charmaz K. *Constructing Grounded Theory; a Practical Guide through Qualitative Analysis*. London: Sage, 2006.

19. Cropper S, Snooks H, Evans A, Pinder J, Shales K. Action research partnerships: contributing to evidence and intelligent change. In: Cropper S, Porter A, Williams G, Carlisle S, O'Neill M, Roberts C, et al. (eds.) *Community Health and Wellbeing. Action research on Health Inequalities*. Bristol: Policy Press, 2007: 73.
20. Bryant A, Charmaz K. (eds.) *The SAGE Handbook of Grounded Theory*. London: Sage; 2007.
21. Morrow E, Boaz A, Brearley S, Ross F. *Handbook of Service User Involvement in Nursing and Healthcare Research*. Oxford: Wiley-Blackwell, 2012.
22. Cooley A, Lawrence Z. *Reward and Recognition: The Principles and Practice of Service User Payment and Reimbursement in Health and Social Care*. London: Department of Health, 2006.
23. Glaser BG, Strauss AL. *The Discovery of Grounded Theory: Strategies for Qualitative Research*. Chicago: Aldine, 1967.
24. Dey I. *Grounding Grounded Theory: Guidelines for Qualitative Inquiry*. San Diego: Academic Press, 1999.
25. Thornberg R. Informed grounded theory. *Scandinavian Journal of Educational Research*, 2015; **56**: 243-259.
26. NHS National Patient Safety Agency. *Information Sheets and Consent Forms: Guidance for Researchers and Reviewers*. 2007. [cited 2015 Mar 19]. Available from: <http://www.hra.nhs.uk/documents/2013/09/information-sheet-and-consent-form-guidance.pdf>
27. National Institute for Health Research. *A Pocket Guide to Good Clinical Practice, Including the Declaration of Helsinki*. 2.1 ed. Leeds: National Institute for Health Research, 2011.

28. British Psychological Society. *Code of Human Research Ethics*. Leicester: BPS, 2014.
29. Ethics Committee of the British Psychological Society. *Code of Ethics and Conduct*. Leicester: BPS, 2009.
30. Tweed A, Priest H. Grounded theory. In: Rohleder P, Lyons AC (eds.) *Qualitative Research in Clinical and Health Psychology*. Basingstoke: Palgrave Macmillan, 2014: 114.
31. Krueger RA, Casey MA. *Focus Groups: A Practical Guide for Applied Research*. 3rd ed. Thousand Oaks: Sage, 2000.
32. Atkin H, Armstrong N, Brandon T, Helme D, Flaherty A, Kemp C, et al. Multiplying perspectives within an emancipatory action research project exploring mental health recovery. *CARN Annual Conference: Connecting Researchers, Connecting Communities*; 2014 Oct 31-Nov 2; Gateshead.
33. Neech S, Eccleston G, Smith K, Tweed A, Bradley E. Involvement in a trainee clinical psychologist's thesis: what can service users and carers contribute as researchers and participants, and why should we listen? *Division of Clinical Psychology Annual Conference*; 2014 Dec 3-5; Glasgow.
34. Brydon-Miller M. *A Whirlwind Tour of Action Research*. [Lecture] 2014 Jun 26; Keele University.

Appendices

Appendix A: Findings Report

Experiences of Service User Involvement in Mental Health Settings. Findings Report, January 2015.		
<p>This study set out to answer the questions:</p> <ul style="list-style-type: none"> • <i>Why do individuals become service user representatives?</i> • <i>What outcomes are achieved in this role?</i> • <i>What can be done to improve mental health service user involvement?</i> 		<p>13 service users with an involvement role were interviewed between June–December 2014. Experiences differed, including involvement in research, peer support, consultation, meeting attendance, and interviewing.</p>
<p>Feeling valued; future service users experiences; giving back; staff influencing opportunities; wellness; and transitions are themes generated from grounded theory analysis, answering the first two research questions.</p>	<p>seen as a continuum of wellness.</p> <p>Involvement has a positive impact, increasing confidence and opportunities for meaningful social activity. Yet, involvement also acts as a trigger for some, where an existing mental health difficulty is maintained with the pressure, short time-scales and expectations that come with the role.</p> <p>There is also a question at this point as to whether service user representatives are really representative of those using services, as the very nature of the role assumes one is well enough and able to think about the experiences of others in order to fulfill duties.</p> <p>Part of moving forward, and the shift in identity is the sense of giving back to staff and service. Giving back implies that individuals are feeling well and on a journey of recovery.</p> <p>Helping others becomes part of the shift in identity, from care-receiving to care-giving, and is often a major driver for starting involvement activities. Individuals want to make a difference in the lives of others, yet at the same</p>	<p>time a process of making sense of own experiences occurs, where individuals reflect on the value and benefit their experience can have for current service users. Both giving back and influencing the experiences of future service users appear to be initial motivations for starting involvement activities.</p> <p>In order to continue involvement activities it is important for service user representatives to feel valued, by other service users, staff and the organisation as a whole. Seeing the impact of involvement has a huge part to play, but payment for involvement activities and staff valuing lived experience also contribute to the feelings of value. When individuals feel valued, confidence tends to increase, and service user representatives may then engage in more involvement activities and move forward in relation to their wellness.</p> <p>As the transition from service user continues, individuals are seen as more of a member of staff within mental health services, voices are more likely to be heard, and it becomes increasingly possible to influence, and promote change for future service users.</p>
<p>It appears that staff influence involvement opportunities and experience, with individual staff members valuing involvement.</p> <p>As service user representatives start the role, there is a move from seeing oneself as a 'service user' to becoming more of an 'insider' within the organisation, where identity shifts towards being part of the organisation. Others perceptions, such as staff, friends, and family members, seem to mirror this individual experience. Some representatives within this transition move towards wanting a career within mental health, and the hope that a cultural change will occur where lived experience will hold greater value when staff themselves are open about mental health difficulties.</p> <p>During this period of transition, representatives notice their mental health, and this can be</p>		

Experiences of Service User involvement in Mental Health Settings. Findings Report, January 2015.

Participants were asked what could be done to improve service user involvement locally. All participants, along with two staff members have been invited to a focus to develop some workable suggestions for to take forward.

Quotes from service user representatives interviewed:

The very basics are 'what is the purpose of involvement?', 'what do you want it to achieve?' and from that point you can then design and develop the processes and procedures to enable that to happen.

It's an education process. The rewards to the service user can be certificates of competence. So that when you then become able to go back into the day to day world, that can be shown.

I think it would be better if they phoned you, than say 'well you can phone us if you want to', because you think 'well, I'm not gonna bother them'. But if THEY... phoned you and said 'how are you feeling now?' Because it's AFTERWARDS that you actually think 'well that had an impact on me'.

I think if you have involvement meetings, that that needs to be fed back, and responsibility needs to lie with somebody who can influence the workforce, for a start...so it needs to be actioned, properly actioned.

The people who are already in something, have an unwritten relationship with each other. They know the system, they've learnt it. People that are sitting on the outside find that difficult to penetrate.

I think they felt very uncomfortable about exploiting me, you know, and not paying me for my time...but yeah, I think there should be perhaps a choice.

Expectations

- Definition of role, clarification of what is expected & the purpose of involvement activities
- Clear confidentiality agreement signed when starting the role
- Clear boundaries
- Updates (e.g. outcome of interviews, results of feedback, update on use of patient videos)

Induction and Training

- Induction booklet
- Initial training period (role-play scenarios, experts delivering training, e.g. staff responsible for recruitment and selection deliver interviewing techniques)
- On-going training (changes within the Trust, working towards a qualification, e.g. NVQ, certificates of competence)

Support

- Involvement coordinator (communication throughout the month, providing confidential support/supervision (outside of department), individual goal-setting/plans for progression)
- Support from professionals regarding how involvement is impacting own mental health (e.g. a psychologist, nurse)
- More opportunities to meet/peer support

Staff Engagement

- Staff need to understand purpose & expectations of involvement
- Provide sheet explaining jargon/acronyms likely to be used
- Meet/provide paperwork prior to involvement activity (e.g. interview applications before the interview day)
- Plan involvement (coproduction from beginning to end)
- Communication to service users on how feedback has been used
- Explain why there may be limits to the number of service user representatives able to attend meetings
- Raise awareness about the role of governors
- Support involvement at a strategic level
- Involvement in 360 evaluations of staff

Diversity and Outreach

- Diversify representatives (draw on different service user representatives for activities, different ethnic backgrounds, long-term and enduring mental health problems)
- Raise awareness (introduction to involvement leaflet clinicians can give to service users, posters & leaflets in waiting rooms, advertise opportunities on volunteer & NHS websites, increase use of technology)
- Accessibility (consider if involvement can still be an option if no funding is available, locality meetings that feed into a main meeting, clear process for how service users contact service user representatives)

Thank you to everyone who has taken part in the study. For more information contact Sophie Neech, Trainee Clinical Psychologist, Staffordshire & Keele Doctorate in Clinical Psychology, Faculty of Health Sciences, Staffordshire University, Leek Road, Stoke-on-Trent ST4 2DF n027407b@student.staffs.ac.uk 01782 294 007

Appendix B: Suggestions for Local Involvement from Interviews

Suggestions for Focus Group

Expectations

- Definition of role, clarifying what is expected & the purpose of involvement activities
- Clear confidentiality agreement signed when starting the role
- Clear boundaries
- Updates
 - Outcome of interviews (who accepted job)
 - Results of feedback
 - Update on use of patient videos

The very basics are 'what is the purpose of involvement?', 'what do you want it to achieve?' and from that point you can then design and develop the processes and procedures to enable that to happen.

There definitely needs to be work on what the work is, and how to get involved, and how it's not like a fulltime job.

Induction & Training

- Induction booklet
- Initial training period
 - Role-play scenarios
 - Experts delivering training, e.g. staff responsible for recruitment and selection deliver interviewing techniques
- On-going training
 - Changes within the Trust
 - Working towards a qualification, e.g. NVQ
 - Certificates of competence

It would be nice if there was some kind of structure of where you could go after doing that... Just sort of some clear progression, or...maybe if there was like an was official, sort of, person they could go to.

I also think that service users and carers...on their pathway to recovery...it's an education process. The rewards to the service user can be certificates of competence. So that when you then become able to go back into the day to day world, that can be shown.

Support

- Involvement coordinator
 - Communication throughout the month
 - Providing confidential support/supervision (outside of department)
 - Individual goal-setting/plans for progression
- Support from professionals regarding how involvement is impacting your own mental health (e.g. a psychologist, CPN)
- More opportunities for user representatives to meet/peer support

I think it would be better if they phoned you, than say 'well you can phone us if you want to', because you think 'well, I'm not gonna bother them'. But if THEY... phoned you and said 'how are you feeling now?' Because it's AFTERWARDS that you actually think 'well that had an impact on me'.

I think that would be good, as a debrief, or even as a one to one...talking to the other service users, they, I know they find it quite difficult sometimes. And you're just LEFT afterwards.

Staff Engagement

- Staff need to understand purpose & expectations of involvement
- Having staff throughout the organisation responsible for involvement (so if one staff member goes it doesn't stop)
- Provide sheet explaining jargon/acronyms likely to be used
- Meet/provide paperwork prior to involvement activity (e.g. interview applications prior to the interview day)
- Planning involvement (coproduction from beginning to end)
- Management regularly attending user forums
- Communication to service users on how feedback has been used
- Explain why there may be limits to the number of service user representatives able to attend meetings
- Raising awareness about the role of governors
- Support involvement at a strategic level
- Involvement in 360 evaluations of staff

I think if you have involvement meetings, that that needs to be fed back, and responsibility needs to lie with somebody who can influence the workforce, for a start...so it needs to be actioned, properly actioned.

It's the whole ethos of involvement... if you've got a voice, you need someone, you need a listener as well. So you need someone to listen. And

people in management have the... clout sometimes to get things done. They can send off the memos and say 'action this'.

Diversity & Outreach

- Diversify representatives
 - Draw on different service user representatives for activities
 - Different ethnic backgrounds
 - Long-term and enduring mental health problems
 - Develop involvement sub-groups
- Raising awareness
 - Introduction to involvement leaflet clinicians can give to service users
 - Posters & leaflets in waiting rooms
 - Advertise opportunities on volunteer & NHS websites
 - Increased use of technology
 - Staff asking patients about their interest in involvement towards the end of their treatment
- Accessibility
 - Consider if involvement can still be an option if no funding is available
 - Locality meetings that feed into a main meeting
 - Clear process for how service users contact service user representatives

The people who are already in something, have an unwritten relationship with each other. They know the system, they've learnt it. People that are sitting on the outside find that difficult to penetrate

Even when you go to like somewhere, you can see that the same person may speak out all the time.

I think they felt very uncomfortable about exploiting me, you know, and not paying me for my time...but yeah, I think there should be perhaps a choice.

Appendix C: Focus Group Flip Chart Data

Experiences of Service User Involvement in Mental Health Settings: Research Focus Group

At the focus group held on 19/01/15 findings of the study exploring *experiences of service user involvement in mental health settings* were fed back to past and present service user representatives who had been involved in individual interviews. Two members of staff with a role/interest in involvement then joined the group, and together the following suggestions for improvements within involvement were developed.

Expectations

- Clarify expectations at start of involvement (and consider if these change)
- Deliver training on what is expected
- Need education around different expectations, ground rules, aims and objectives, purpose and expectations, and contract, depending on the involvement role (e.g. asking 'what is the situation?')
- Create mentoring roles to give guidance (e.g. unwritten rules and etiquette)
- Consider if involvement should be consistent, or whether lived experience is needed for difference

Induction and Training

- Deliver interviewing training (could be run by HR) to maintain consistency and ensure service users are adequately prepared
- Depth and quality of induction and training depends on which staff member facilitates
- Develop a framework
- Clarity of roles within service user involvement (e.g. what are the rules for the role?)
- Develop further in-house training and ongoing appraisal
- Deliver annual service user involvement training event
- Integrate training for staff and service users (e.g. 'best practice for recruitment')
- Provide opportunities for service users to feel safe, but not constrained or 'professionalised'
- Train staff in involvement (e.g. what is expected of service users and what is needed, such as prior preparation for interview panels, to follow policy, etc.)

Support

- Support needed at different stages (before, during, and after involvement activities)
- Develop consistency throughout the organisation
- Following policy (where in existence) in relation to involvement
- Key staff members (e.g. chair of interview panels) take time/responsibility for ensuring service users feel prepared
- Support outside of involvement activity
- Provide opportunities to talk to someone quickly, if needed
- Give examples of how current services and systems work (during induction), especially when involvement does not include contact with a specific team
- Consider through-flow of individuals taking part in involvement activities

Staff Engagement

- Address acronyms and jargon
- Develop collaborative partnership working/meeting as equals
- Numbers of staff/service users to be 50-50
- Avoid tokenism (involvement activity should not just tick a box)
- Staff and service users of teams talk together, then a representative feeds discussion back into service user forums
- Consider how to increase involvement opportunities for current service users
- Consider how to offer involvement opportunities to service users as they approach discharge (e.g. survey)
- Service users becoming involved in care plan and involvement can become part of a natural progression
- Foster a culture of value and respect
- Create declaration of confidentiality
- Consider volunteering and paid roles, and where involvement fits

Diversity and Outreach

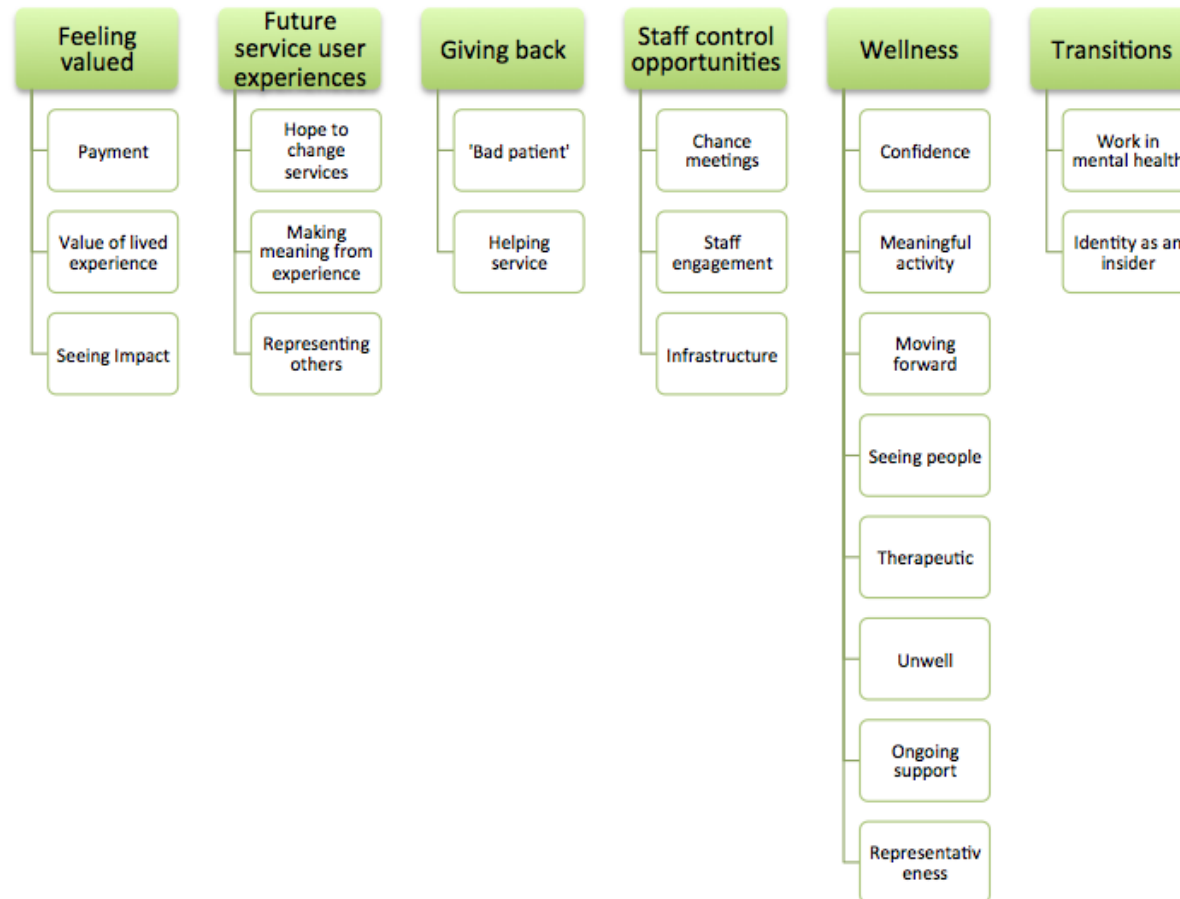
- Create representative roles to speak on behalf of different subgroups and regions (for feedback and to find out what is most relevant to that region)
- Develop communication (e.g. computers, newsletters)
- Link care coordinators' roles to involvement
- Develop active projects to engage groups who are under-represented
- Create a structure to monthly 'listen and respond' groups

Appendix D: Focus Group Introduction

Experiences of Service User Involvement – Focus Group 19/01/15

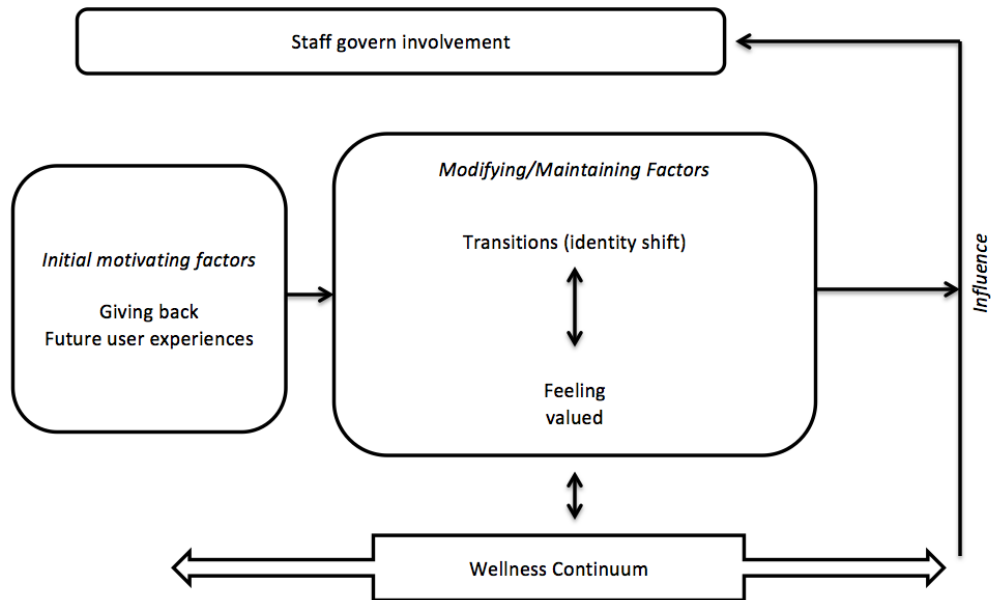
- Purpose:
 - Feedback findings of the study
 - Promote discussions to take things forward
- All encouraged to take part
- Want people to be able to talk freely
- Respectful, polite & open conversation
- Confidentiality
 - No repercussions
 - Want to be able to use ideas & feedback outside of this group, but we all need to agree not to share names & opinions of specific individuals
 - Only data on the flipchart will be shared with the Trust
- Recording
 - Use names today – will be made anonymous for transcript
 - Try not to talk over others
- Phones on silent
 - Please leave quietly if necessary
- Role of facilitators
 - To guide conversation
 - If you're talking a lot, we may ask you to give others a chance
- Format
 - PowerPoint slides & handout to follow
 - Overview of study
 - Findings from analysis
 - Each slide & then comments from group
 - Break (15 mins, until 11am)
 - Staff join group
 - Suggestions
 - Each slide & then comments from group
 - Debrief
 - Questions at end - & can contact researchers afterwards
- Introductions (name & brief example of involvement role past/present)

Appendix E: Grounded Theory Coding Structure

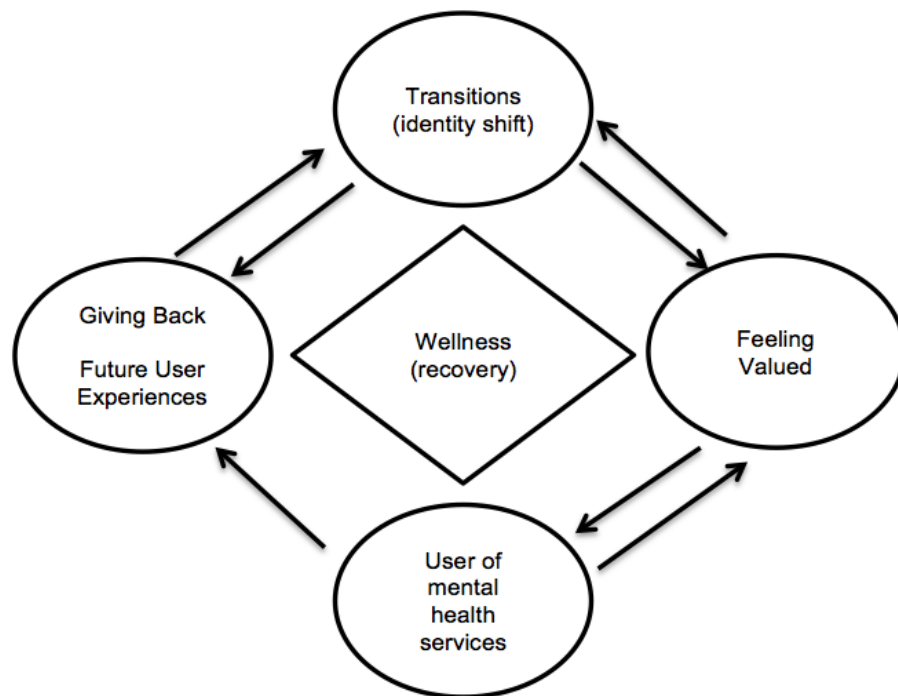


Appendix F: Conceptual Framework

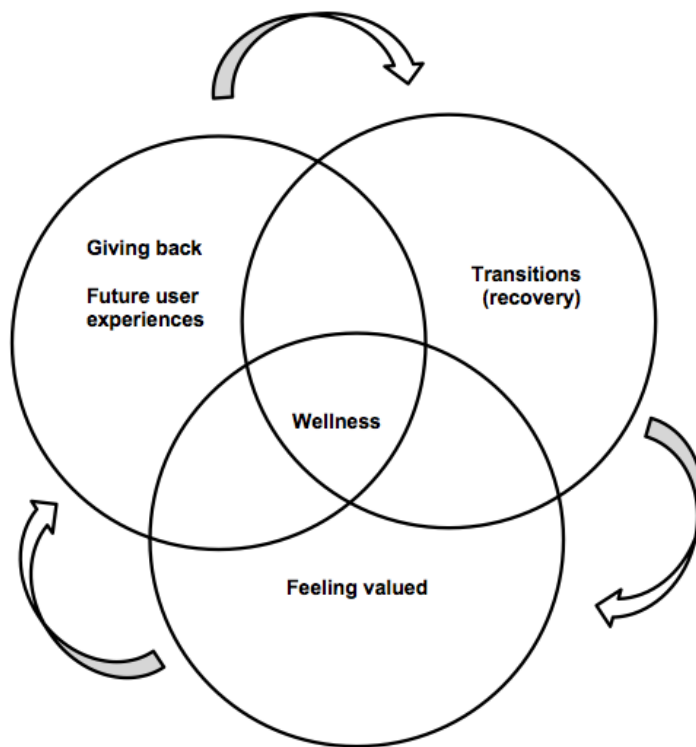
The process of developing a conceptual framework went through a number of stages, with feedback sought from later participants and the research team.



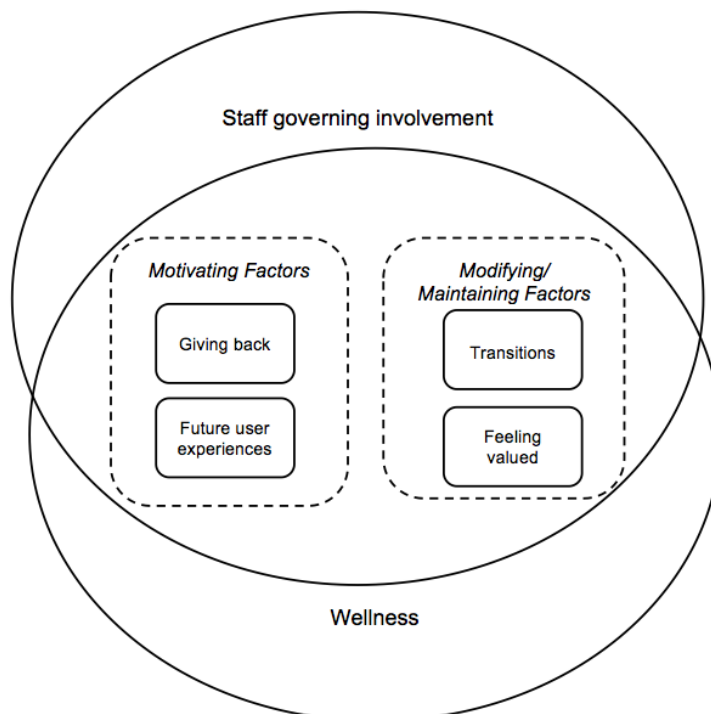
Version 1



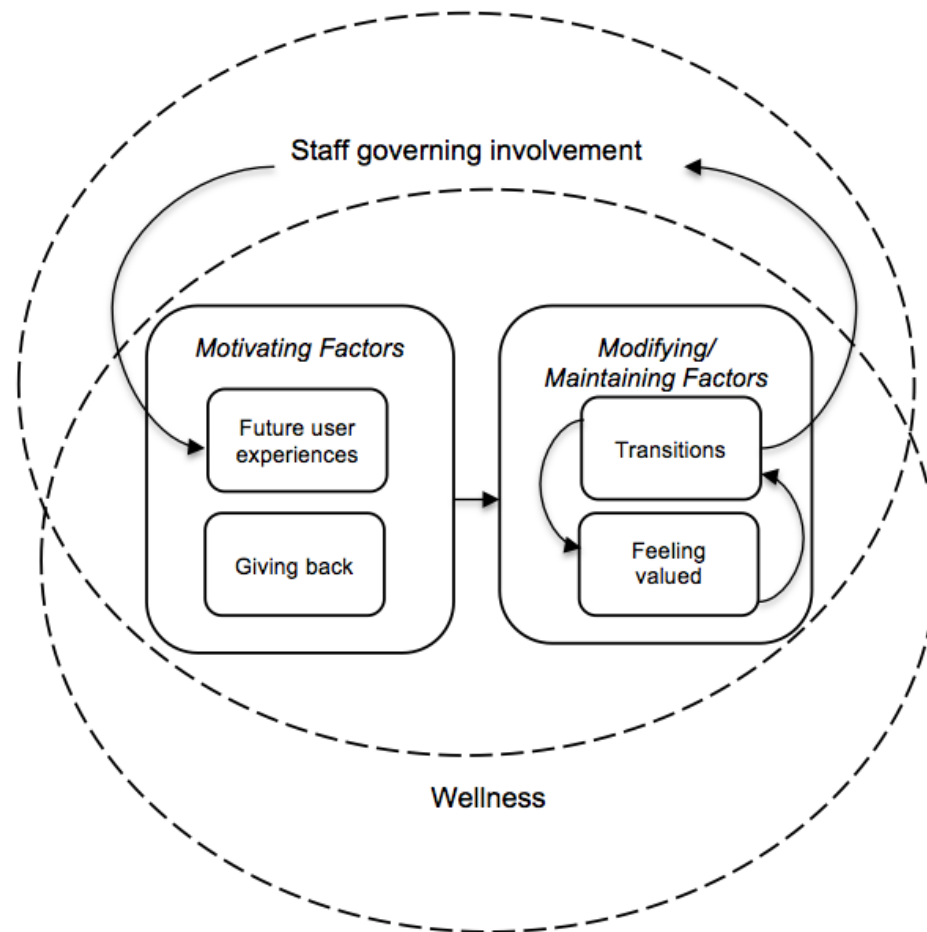
Version 2



Version 3



Version 4



Version 5 (final version)