A scoping review of the literature on the involvement of service users in personality disorder services

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Background. Service user involvement is receiving increasing support from mental health policy makers, service planners and research commissioners. However, we lack a good understanding of the nature and extent to which service users are involved in personality disorder (PD) services and the effects of involvement in these services.

Objectives. To review and appraise published sources; increase understanding about service user involvement in PD services; and highlight knowledge gaps and related issues.

Methods. A scoping review methodology was adopted. Data were 'charted' to illustrate the landscape of writings and views and a qualitative analysis synthesized the results in terms of key emergent themes.

Results. Only a small amount of published work was identified with significant gaps in the literature. Effects were reported mostly in terms processes and emotional and practical benefits for service users. Emergent themes were wellness and health, recruitment and support for service users.

Conclusions. This scoping review uncovered a lack of published work despite service user involvement being a key strand of health policy. There is a need for outcomes-focused research regarding service user involvement. Successful user involvement in PD services requires attention to be focused on the context, recruitment, support and 'wellness' of service users.

Introduction

The involvement of service users, including people with personality disorder (PD), is receiving increasing support from mental health policy makers and service planners in the United Kingdom (Department of Health 1999, 2009). Similarly, research commissioners are beginning to require researchers to engage with service users and to involve them in the various stages of a study (Public Health Agency 2010). However, we lack good understanding about the nature and extent to which service users are involved in activities such as the practice, planning, organization and delivery of services relating specifically to the field of PD services. We know even less again about the effects of service user involvement in PD services.

Involving people who receive support from mental health services in their care occurs in various capacities, structures and remits (Diamond *et al.* 2003; Simpson & House, 2003). A frequently used starting point for

consideration of levels of user involvement is Arnstein's Ladder of Citizen Participation (Arnstein 1969) and levels or rungs of consultation, collaboration and consumer (or user) control adapted and applied to describe and evaluate involvement in research and services (Hanley *et al.* 2004; Strømme *et al.* 2006). Consultation is described as asking for views and using these views to inform decision making; collaboration, as active, on-going partnership; and user control, as positioning the locus of power and decision making with service users.

The last decade has seen important changes in PD policy and service provision [e.g. *Personality Disorder: no longer a diagnosis of exclusion*, Department of Health (2003*b*); and *The Personality Disorder Capabilities Framework*, Department of Health (2003*a*)]. NICE guidelines for the treatment of borderline PD and antisocial PD were published in January 2009 (National Institute for Health and Clinical Excellence, 2009ab). The research in this area has highlighted that service users with a PD diagnosis have had negative experiences of mental health services (Horn *et al.* 2007; Rogers & Dunne 2011).

There has been little analysis of public involvement in health and social care research (Staley 2009). A number of systematic reviews have focused on the

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effects of user involvement (Crawford 2002; Strømme *et al.* 2006). However, none have considered specifically the area of PD. This scoping review considers two arguably difficult conceptual areas 'service user involvement' and 'PD' in order to consider potential learning for policy and practice.

Methods

A scoping review methodology (Arksey & O'Malley 2005) was employed for a number of reasons. First, service user involvement may be considered to be a complex intervention and the review methodology needed to be broader in scope than the (more specific, narrow) conventional systematic review in order to capture and examine this aspect. Second, an early investigative search indicated a lack of peer-reviewed work. Finally, a scoping methodology is appropriate when the parameters of a topic are unclear and the intention of a study is to 'map' the field and identify research gaps.

Stage 1: identification of the research question

The research question revolved around and was informed by the literature about user involvement in PD services. (Crawford 2002; Arksey 2003).

Stage 2: identification of relevant studies

In keeping with a scoping review we adopted a search strategy, which involved searching different sources. Electronic databases and references of papers in the review were searched; a number of clinicians and researchers in the field were contacted; and an internet search was conducted.

Search strategies for electronic databases were developed with an information specialist. Initial searches of three electronic databases (Medline, CINHAL and PsychINFO) were undertaken in order to inform the scoping search. Existing reviews of service user involvement were examined and their search strategies and terms were incorporated into the scoping methodology (Crawford 2002; Strømme *et al.* 2006). The scoping search strategy combined 'PD' in combination with other keyword terms that are used to describe 'service user involvement'. An example of a representative search is included in Fig. 1.

Titles and abstracts were reviewed in the initial exercise and identified papers were reviewed in full against the search criteria for inclusion. Identified literature was also reviewed for further key terms which could be included in a final search.

The final search was conducted using the keywords piloted in the initial search as no further key terms were identified. The keyword search was run in seven further databases (ASSIA, Ingenta, SAGE, Science Direct, Social Sciences Citation Index, Social Sciences Abstracts and Sociological Abstracts) to identify relevant studies and writings in the social sciences. Papers were reviewed in the same way as those identified by the initial search of the initial three databases.

The method used for the internet search was to employ a strategy of searching four main websites as an initial step (Centre for Mental Health 2011; Emergence n.d. Involve 2011; Personality disorder n.d.). These websites were chosen as they are prominent mental health, PD and service user websites. Links identified on the websites were followed.

Stage 3: study selection

Criteria were devised iteratively following familiarization with the literature and then applied to the identified literature in order to 'map' the field. This approach differs from the methodology used for a systematic review where specific *a priori* inclusion and exclusion criteria are devised (Arksey & O'Malley 2005). Scoping reviews tend to be non-systematic in nature and tend to focus on the breadth of coverage of the literature conducted on a topic rather than the depth (Rumril *et al.* 2010). The approach was necessary in order to scope the as yet unchartered field of user involvement in PD services.

We included papers which described service user involvement in planning, monitoring, developing or commissioning services; teaching or delivering services; development of guidelines or patient information material; research (other than as subjects) and advocacy and peer support. Papers were only included if they also addressed PD services. Papers were excluded if they described service user involvement in individual treatment choices. Arguably, a service user's involvement in their own treatment choices has an effect on services and their development and, generally, this aspect is recognized as an important part of mental health treatment. We focused on the area of service user involvement where the service user voluntarily or in a paid capacity agrees to offer their skills and experience in order to influence services for others with the same condition – we did not include patient involvement in individual treatment choices as this is a separate albeit-related aspect and requires individual systematic attention in its own right. No restriction was placed on type of study for research-based reports of service user involvement. The review also included non-research-based reports if they described service user involvement in terms of the categories noted above. Papers were restricted to English language but were not restricted by date. Seventeen papers met the inclusion criteria for this review (Fig. 2).

1. exp Personality Disorders/88

2. (personality adj1 disorder*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

3. 1 or 2

4. exp Consumer Participation/

5. ((consumer adj1 advocacy) or (peer adj1 advocacy)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

6. Consumer Advocacy/

7. ((client* or consumer* or patient* or user* or stakeholder* or lay* or citizen* or public) adj (empower* or involve* or particip* or represent* or collaborat* or consult* or contribut* or engagement* or deliberat* or dialogue* or opinion*)).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

8. ((expert adj patient*) or (expert adj by adj experience) or expert-by-experience).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

9. (participatory adj intervention*).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

10. 4 or 5 or 6 or 7 or 8 or 9

11. 3 and 10

12. limit 11 to (english language and humans)

Fig. 1. Search strategy for Medline (1950 to current).

Stage 4: charting the data

The technique adopted in this review was a 'descriptive-analytical' method, which involved applying a common analytical framework to all the primary research reports and collecting standard information on each study.

An adapted version of the 'PICO' formula was used to chart the data (Centre for Reviews and Dissemination 2009) None of the studies featured a comparison group and so consideration was given to population, intervention and outcome in devising the domains for study.
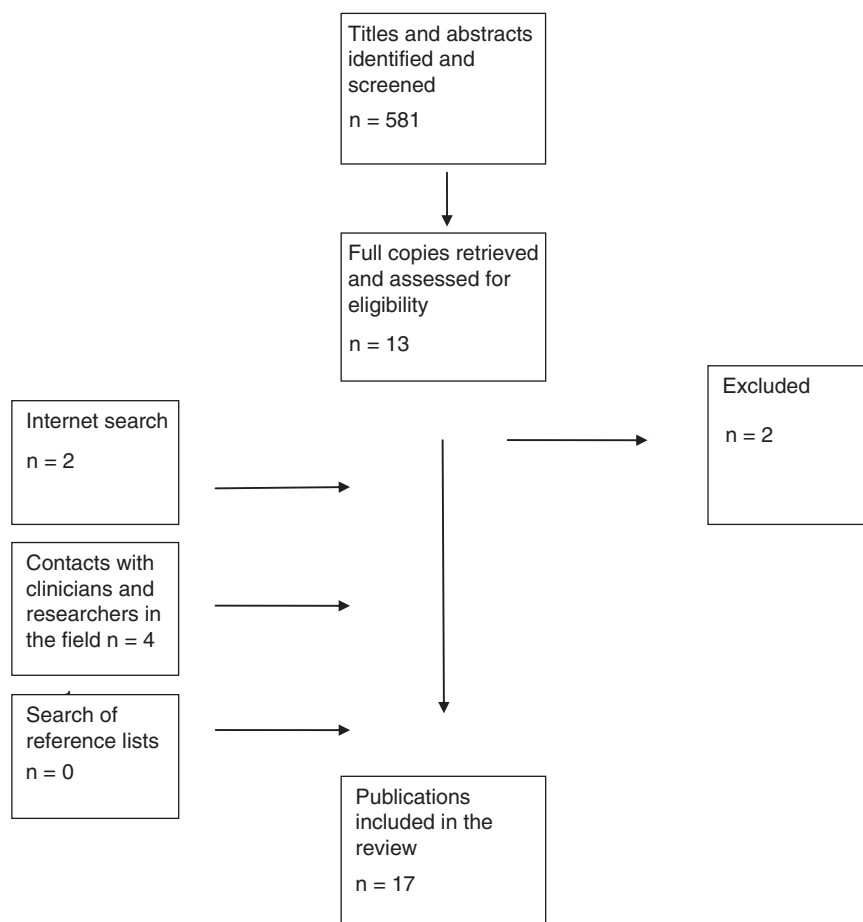
Fig. 2. Flowchart showing selection process based on scoping methodology (Arksey & O'Malley 2005).

We divided papers into research-based (empirical) studies and papers which were articles and commentaries exploring relevant themes. The series of data captures and information domains were organized into two tables for subsequent analysis. Table 1. charts the data extracted from the empirical papers and Table 2. charts the data extracted from the articles/commentaries. Data about the 'poplulation' was captured through a description of the methodologies employed for empirical papers and for both types of paper the context of service user involvement within the literature. 'Intervention' data was captured in terms of the form of service user involvement and the level of involvement as well as whether service users or professionals initiated the involvement. This data capture was informed by the approach described in the systematic reviews by Strømme *et al.* (2006) and Crawford (2002). Charting in brief the main findings for empirical papers (Table 1) and a brief summary of discussion for commentaries (Table 2) captured the nature of outcomes or effects. Scoping reviews tend not to evaluate the quality of studies in the review (Rumril *et al.* 2010).

Stage 5: collating, summarizing and reporting the results

The data was organized and tabulated as described and then analysed further through repeated reading and sorting and finally presented in a narrative form. The iterative approach of repeated reading and sorting allowed identification of key themes or links. This second level thematic analysis is described in the results.

A consistent, explicated approach to charting the data and presenting the results so that the results may be checked against the original data was employed by the first author and the second author checked work at every stage.

Results

Seventeen papers were identified which included diverse material including research and articles/commentaries on service user involvement in PD services. Table 1 presents information which was extracted from empirical studies: methodology employed; the context of service user involvement; the form and level of user involvement; whether service users or professionals initiated

Table 1. *Data that were extracted and charted from empirical studies*

Paper	Methods for research-based papers	Context of SUI within paper	Form of service user involvement	Level of SUI	Initiated by	Main findings
Balls (2010)	Evaluation of a preparatory training package and SUI in teaching and training via semi-structured interviews ($n = 6$)	SUI in teaching, training and preparatory programme	Teaching and training	Consultation	Professionals	Key themes: personal and professional gains, importance of team work, satisfaction with teaching, lack of organization, difficulties with communication, and recruitment issues
Barlow *et al.* (2007)	Thematic analysis of group discussions and development of guidelines from analysis ($n = 13$)	SUI in group discussions	Group discussions	Consultation	Professionals	Service user and trust guidelines produced following SUI in group discussions
Crawford *et al.* (2007)	Evaluation of 11 pilot services using multiple methods including an organizational evaluation, a user-led qualitative evaluation, a cohort study and a Delphi study	SUI as one element of evaluation	SUI in pilot services	Examples varied	Examples varied	SUI varied between services. Recognition, value and empowerment of SUI appreciated by SUs. Difficulties and positives of SUI discussed
Gillard *et al.* (2010)	Thematic analysis of reflective writing exploring expectations and feelings regarding involvement in research ($n = 7$)	Reflection on research process involving SUs	SUI in research	Collaboration	Joint commissioning of research with service user and carer organization	Researchers reported high expectations of coproduction mostly met and findings of research different with greater credibility due to SU and carer involvement
Hogard & Ellis (2010)	Evaluation of Managed Clinical Network through assessment of outcomes, processes and multiple stakeholder perspectives. Qualitative and quantitative data-gathering methods	SUI as one element of evaluation of managed clinical network for personality disorder	Varied evidence of SUI in PD services	Examples varied	Examples varied	Conference on SUI, development of newsletter and involvement in setting up and evaluation of day treatment services as evidence of SUI within MCN
Moran *et al.* (2008)	Evaluation of three pilot forensic PD services using multiple methods including a cross-sectional survey of service users, a description of service characteristics, investigation of the outcome of service users, an investigation of team outcomes and a synthesis of data collected	SUI as one element of evaluation	SUI varied greatly between services	Examples varieed	Professionals	Provision for SUI at levels beyond level of own care varied considerably
Ramon *et al.* (2001)	Evaluation of quantitative and qualitative research undertaken by four SURs ($n = 50$) including quality of data and interviewee response	SUI in research described within research paper	SUI in research	Collaboration	Professionals	Quality of data collected by SURs was good. Indirect indications of satisfaction of interviewees. SURs empowered by involvement. SURs required considerable support from co-coordinator
Rawlings (2003)	12-month participant observation study on three sites with thematic analysis of data	SUI in development of three therapeutic day programmes	SUI in planning of TC day programmes	Consultation	Professionals	Descriptive analysis of planning processes with description of three difficult areas: recruitment, effects of work on service users involved and quasi-staff role
Turner *et al.* (2011)	Qualitative research ($n = 6$) co-produced by three researchers including one SUR	Reflections on SUI in research	SUI in research	Collaboration	Service user-led organization	Interviewees inspired and encouraged by SUR. Researchers felt broader and more comprehensive range of data were collected and evaluation was lengthened but benefitted from coproduction

SUI, service user involvement; PD, personality disorder; TC, therapeutic community; MCN, managed clinical network; SUR, service user researcher.

Table 2. *Data that were extracted and charted from commentaries*

Paper	Context of SUI within paper	Form of service user involvement	Level of service user involvement	Initiated by	Main findings/discussion of service user involvement
Castillo (2005)	Description of client-led model for treatment	Client-led treatment	User-control	Service users	Description of client-led model and client report of TC experience as positive
Cosh (2010)	Description of consultation project with staff and service users	Consultation completed by a service user led organization	User-control	Service users	Written material produced for SUs and staff. SUs felt empowered by taking part
Faulkner *et al.* (2008)	Description of Service user led research	SUI in research	Collaboration	Professionals	Challenges and successes of research discussed. Outcomes related to personal development among SURs. An individual perspective on involvement given. Team felt SUI in analysis gave an extra level of validity
Haigh *et al.* (2007)	SUI in National PD Development Programme	SUI in National PD Development Programme	Consultation and collaboration	Professional initiation of majority of work with description of one piece of user-led work	Description of SUI in National PD Development Programme
					Development of capabilities, wellness criteria and code of conduct. Benefits to service users discussed. Need for authentic meaningful involvement and emphasis on wellness
Jackson (2007)	Description of exhibition of SU art	User-directed community interest company	User-control	Service users	Discussion of organization of arts-based project including interviews with key participants. Themes of: challenging stigma, installation of hope and recovery. Aim to set up regional service user networks
Jones & Stafford (2007)	SUI in PD services	Varied evidence of SUI	Collaboration	Professionals	SUI in writing of funding bid, training, service advocacy and co-facilitation of groups. Employment in career structure. Staff perspective
Roberts (2006)	Discussion of SUI within social context	N/A	N/A	N/A	Discussion of difficulties of service user representation and the 'authentic user voice'. Concern over effect of social division and structural inequality in the context of SUI
Sundaram (2010)	PD service provision in the context of UK policies and guidelines	Service user involvement in lobbying for services	N/A	N/A	Policy analysis including stakeholder views in context of UK Department of Health policies and guidelines. Emphasis on importance of collaboration

SUI, service user involvement; TC, therapeutic community; PD, personality disorder; MCN, managed clinical network; SUR, service user researcher.

involvement; and a brief outline of the focus of findings. Table 2 presents information extracted from articles and commentaries: context of service user involvement; form and level of user involvement; whether service users or professionals initiated involvement and a brief outline of the discussion.

Thematic analysis

Importance of context

Many studies had associations with the English National PD Development Programme. User involvement began as a parallel process to the main work of the programme. The reported early benefits of user involvement led to further user involvement as the programme developed and user involvement became integral to new projects and developments (Haigh *et al.* 2007).

Many of the PD services and research projects had a therapeutic background. It is noted within the two evaluations of PD services that services based on therapeutic community (TC) models have an integral service user involvement component (Crawford *et al.* 2007; Moran *et al.* 2008). Service users who experienced treatment within a TC tended to bring the rules and culture of a TC to the development of new services and to act as 'culture carriers' (Rawlings 2003). Haigh *et al.* (2007) noted that '…projects like Thames Valley Initiative (TVi) and the South West London Service User Network (SUN) take their model of service user involvement from the themes of democratization and empowerment that have been alive for many years in residential TCs such as the Henderson, Cassel and Francis Dixon Lodge'.

Roberts (2006) and Sundaram (2010) highlighted the importance of policy and service development. In particular, Roberts (2006) noted the importance of social context including social division and structural inequalities with concern that the difficulties of representing a diverse population may be overlooked.

Wellness and health

The wellness or health of users was a common theme with indications that there was a need for users to monitor or evaluate their health and for relevant parties to be aware of the sometimes demanding nature of the service user role. The need to negotiate their own mental health in the context of a demanding piece of work was a serious challenge to user researchers (Faulkner *et al.* 2008). There was an expectation that service users who engaged in involvement-like activities met 'wellness criteria' (Balls 2010).

The development of wellness criteria and a code of conduct are tools designed to place service users (or ex-service users) at the centre of considerations. According to wellness criteria, service users should be facilitated to assume responsibility for doing whatever is needed in order to safeguard their health (Haigh *et al.* 2007). Focusing on 'wellness' rather than 'illness' was intentional in order that, for example, taking time out from responsibilities could be seen as a positive step that preserved wellness and allowed a service user to return to work without the negative associations of emotional or mental ill health. Also important was the need to match the type of involvement or participation to the wellness of an individual service user (Haigh *et al.* 2007; Jones & Stafford 2007). Significant difficulties may arise among service users when one of them has a crisis (e.g. attempted suicide) and appropriate supports are required to take account of this type of event (Rawlings 2003).

Support for services users during involvement activities

Support for service users was the second common theme to emerge. A number of papers reported that a great deal of support was needed for projects involving service users including administrative and emotional support. Some user researchers may go through a crisis during a research project and sufficient numbers should be trained to take account of the difficulties and to enable users to return to the project after a crisis (Ramon *et al.* 2001). The support required in service user research projects was greater than anticipated; and providing and resourcing sustained support for user-researchers and project co-ordinators of studies was recommended (Ramon *et al.* 2001; Rawlings 2003; Barlow *et al.* 2007; Haigh *et al.* 2007; Balls 2010). The Service User Research Group England guidance was utilized along with a flexible team approach to projects that allowed users to cover for each other and to drop in and out of a project as necessary in the context of solid formal and informal peer support (Faulkner *et al.* 2008).

Recruitment of service users

Recruitment procedures appeared to be important contributing factors to successful user involvement. In some instances difficulty was experienced in recruiting sufficient numbers of users (Crawford *et al.* 2007; Moran *et al.* 2008). Difficulty involving a sufficient number of users was experienced when recruitment was informal and based on recommendation from clinicians (Barlown *et al.* 2007). Some professionals initiated user involvement and evolved selection criteria for future service users (Haigh *et al.* 2007; Balls 2010). Service user networks were also used for recruitment (Ramon *et al.* 2001; Faulkner *et al.* 2008) and

Gillard *et al.* (2010) involved recruitment through a service user and carer-led organization.

Three projects outlined core requirements or capabilities that users were required to possess (Haigh *et al.* 2007; Faulkner *et al.* 2008; Balls 2010). Capabilities referred generally to skills such as the ability to look beyond individual circumstances to address the broader needs of people with PD. These papers described a requirement for a lived experience or knowledge of the difficulties associated with PD. Service users felt that a 'readiness' for training and an individual's willingness to participate in training activities were important (Balls 2010) and Jones & Stafford (2007) described the development of a career structure for the employment of experts by experience.

Differences were observed between the employment of service users who had previously experienced treatment in a TC and non-TC service users (Rawlings 2003). The ex-TC patients were less impulsive, made more constructive decisions about dealing with crises and group dynamics during meetings were more stable. A difference was also observed between early recruitment and later recruitment. Service planning developed more quickly when recruitment occurred later and initial project operational issues had been resolved. Programmes formed more slowly to fit with particular local services and needs when recruitment occurred early in service design and development.

Discussion

Mismatch between policy, practice and research attention

This scoping review of the literature relating to service user involvement in PD services found only 17 papers including non-research-based work despite adopting a broad scoping methodology. There was no reference in the published literature in the review regarding this lack of attention, which is surprising given the increasing emphasis on user involvement, which is advocated in policy documents. In particular, the scoping review did not identify any papers from outside the UK. There were no outcome-focused or economic evaluations of service user involvement

The importance of context

A number of studies showed an association with the English National PD Development Programme. Overall, the literature seemed to indicate a progression from professional, top-down initiated service user involvement to a bottom-up, user-initiated approach. For example, the National PD programme provided an impetus and perhaps resources for user involvement but increasingly service users assumed ownership for

involvement. However, it is surprising that only one paper described service user involvement in forensic PD services (Moran *et al.* 2008) especially in the light of the focus on Dangerous and Severe Personality Disorder Services as part of the National PD programme.

The development and evolution of user involvement in PD services merits further research in order to improve understanding about factors that foster successful user involvement and greater ownership by users. These factors may include elements of a TC culture for example democracy, empowerment and a flattened hierarchy.

The 'mechanisms' of user involvement

In common with the findings of other reviews, the literature is varied in the detail and attention given to descriptions of user involvement as an 'intervention' (Crawford 2002; Strømme *et al.* 2006). Lack of detailed information created difficulties in terms of assessing the form and level of user involvement and within some papers a wide variety of activities were described but not elaborated upon. Collectively, the literature suggests that the form and level of involvement are important to understanding meaningful user participation.

The effects or outcomes of user involvement

The findings or outcomes of studies were mainly based on processes and related to the delivery of user involvement. Emotional or practical benefits for service users were noted in some studies. Emotional benefits included empowerment, validation and the installation of hope and to a lesser degree changed expectations. Practical benefits included finding pathways back to work, the production of guidelines and the production of research. None of the papers described outcomes or effects in terms of PD services or treatment and changed clinical outcomes. A similar finding has been observed in studies of user involvement in other areas (Crawford 2002; Strømme *et al.* 2006; Staley 2009). Greater expansion of assessed outcomes may give a better indication of what can be achieved by service user involvement. Outcomes should be compared against stated aims. More importantly, perhaps, is the need to incorporate the concept and measurement of 'personal recovery' into the assessment of outcomes (Donnelly *et al.* 2011).

Wellness, health and support for service users

Wellness and health emerged as a key theme though arguably it has not been given the attention it requires. Health difficulties amongst service users were reported in papers but they were not considered as an outcome

or finding of the work. It is important that both positive and negative outcomes are assessed and appraised in order to increase our understanding of user involvement in PD services. Similarly, drop out from user involvement is important but it has not received sufficient attention. Jones & Stafford (2007), for example, reported positive results from user involvement without discussion of the poor response to questionnaires and the reasons for dropping out of the study. As noted earlier, wellness criteria have been devised as a tool to help service users safeguard their health (Haigh *et al.* 2007). The question of how best to safeguard and respond to wellness and health is linked to the issue of the support for service user involvement, which has tended to be underestimated.

Recruitment

Recruitment was described as difficult in a number of papers whereas other papers discussed recruitment processes in detail. Recruitment practices varied and in two papers an evolving understanding of recruitment was evident with initial selection based on recommendations by clinicians and then later selections were based on developed selection criteria (Haigh *et al.* 2007; Balls 2010). This evolution would appear to be linked to the progression from professional top-down initiated work to user-led, bottom-up initiated work.

Core requirements or capabilities were described in three papers (Haigh *et al.* 2007; Faulkner *et al.* 2008; Balls 2010). These papers described a lived experience or knowledge of the difficulties associated with PD. Service users may fulfil different roles depending upon their stage of treatment and wellness (Haigh *et al.* 2007) and service users who have not experienced treatment yet may be less able to engage in demanding service user roles. Roberts (2006) argued that it was important all service user voices are heard in the development and planning of services including those who are not actively engaging in treatment.

Limitations of this scoping study

In general, the lack of literature affords only tentative conclusions about the key issues and more research is required to identify the differential impact of key aspects of user involvement. In addition, there was a lack of information about the form and level of involvement. Most papers reported small numbers of users involved in services and for research-based papers there was a lack of detail regarding methodology. It is possible that a wider search may add to the literature, for example, by including additional electronic databases and using terms relating to forensic mental health services as well as contacting a wider range of clinicians, researchers and user involvement bodies to

identify further grey literature. However, given the breadth of the search strategy used in the scoping review it is unlikely that any new substantive material would be uncovered. The scoping study could potentially be strengthened by a consultation exercise to inform and validate findings from the main scoping review (Arksey & O'Malley 2005).

Further research

The lack of published research in user involvement in PD services is significant (and there are few suggestions for further research in the published literature). There was insufficient research to identify with confidence the effects of user involvement in PD services or the key elements to successful user involvement. The extent to which service user involvement in this contested area of mental health provision differs from other services requires further consideration and attention. This review adds to the literature by indicating a number of elements of user involvement worthy of further study. It is suggested that an appropriate framework for future research is to consider the context, mechanism and outcome of user involvement. Furthermore, consideration of user involvement as a complex intervention using Medical Research Council (MRC) guidance in designing appropriate research methodology may be helpful. The MRC guidance for developing and evaluating complex interventions (MRC 2008) outlines a development-evaluation-implementation process. This review provides a starting point for the development of interventions, which could be subjected to piloting and feasibility testing before formal evaluation.

The elements and themes that emerged from the review provide hints and insights about the development of user involvement in PD services. For example, a common link between studies and reports – a TC – points to the elements of a TC culture which may lend themselves to effective user involvement (e.g. democracy, empowerment and the flattened hierarchy of the TC). A conceptual analysis is required in order to clarify potential processes or mechanisms (e.g. democratic relationships) and outcomes (e.g. feeling empowered).

Conclusions

This scoping review of the literature on the effects of user involvement in PD services has revealed only a small amount of published work despite policy support for user involvement in health services. Significant gaps in the literature were evident suggesting that investment in research into user involvement in PD services has not followed policy support. There are considerable difficulties in considering meaningful user involvement including lack of exploration of the form and level of

involvement. The effects or outcomes of user involvement were mainly based on processes and related to the delivery of user involvement. An understanding of the effects of user involvement and the best means of assessing these will become increasingly important due to the need to justify the resources required for user involvement in a current climate of financial austerity.

While there was insufficient research to identify with confidence the effects of user involvement in PD services or the key elements to successful user involvement, this review points to a number of potentially fruitful areas for further study such as the 'cultural' components of user involvement. The MRC guidelines for developing and evaluating complex interventions (MRC 2008) may provide a framework for future research and the results of this scoping review may be used to contribute to the development of an intervention that incorporates a cycle of piloting, modelling, feasibility, testing and appraisal.

Acknowledgements

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