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South West Yorkshire Partnership NHS
NHS Foundation Trust

Mental Health and Learning Disabilities
Research and Practice

Volume 7 Number 1
Spring 2010

Mental Health and Learning Disabilities Research and Practice, 2010, 7, 77-91

Innovations in User Involvement: The Development and Evaluation of a Preparatory Training Package for Service User Representatives

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Abstract

Background: Research has highlighted that poor preparation and/or lack of appropriate skills may be a barrier to effective and credible implementation of User Involvement (UI) in mental health services.

Aims: To describe the development and evaluation of a unique training package delivered to members of a service user reference group to enable them to contribute to staff training aimed at improving attitudes towards borderline personality disorder.

Method: Semi-structured individual interviews were conducted with six participants who had received the training package.

Results: An analysis of participants' comments revealed six key themes: personal and professional gains, importance of team work, satisfaction with teaching, lack of organisation, difficulties with communication and recruitment issues. All participants rated the training package very highly, but inappropriate recruitment of user representatives and a lack of funding and subsequent consistent practical support were cited as barriers to effective UI.

Conclusions: Careful selection and training of user representatives is vital to maximise the efficacy of UI, and ensure that it is a positive experience for user representatives. Further robust comparative research is required to demonstrate the usefulness of UI, and inform evidence-based practice.

Special thanks to Paul Bushell, Rachel Chun, Viv Cowdrill, Dee Gibson, Lesley Herbert, Helen Moreton, Steve Parker and Valerie Walsh for their invaluable contributions to this paper. Thanks also to Professor Paul Chadwick for his comments on an earlier draft of this paper.

Key words: User Involvement, Consumer Involvement, Service Users, Training, Borderline Personality Disorder

Introduction

The role that service users can play in improving health care delivery has been a key aspect of policy making since the 1990's, featuring in documents such as "The NHS and Community Care Act" (Department of Health, 1990) and "The Patient's Charter" (Department of Health, 1991). The National Service Framework (NSF) for Mental Health states that "people with mental health problems can expect that services will involve service users and their carers in planning and delivery of care" (Department of Health, 1999, p. 4). User involvement (UI) in mental health services may be individual or collective (Campbell, 2001), ranging from an individual actively contributing to writing their own care plan to consultation about improving service delivery, respectively.

However, support for UI is not universal (see Diamond, Parking, Morris, Bettinis & Bettesworth, 2003; Forbes & Sashidharan, 1997; Rush, 2004). Tait and Lester (2005) highlight that UI is a current buzzword, but may not necessarily translate from theory to effective practice. This view is supported in the UI literature, the dearth of which demonstrates the disappointing lack of research and dissemination of best practice in this area. One large cross-sectional survey across Greater London found that none of the Trusts had UI systems that met national standards (Crawford, 2003). Other research suggests the majority of local service user organisations are small and poorly funded, which is likely to hamper their ability to achieve change (Wallcraft, 2003).

Despite a lack of research, poor methodology and small sample sizes, the literature suggests that UI can have a positive impact upon the training of mental health workers. In 2005 the Royal College of Psychiatrists announced that all psychiatric trainees must receive training from service users or carers. Comparative studies suggest that trainees in user trainer groups show significantly more positive attitudes towards UI, less stigmatising attitudes and greater levels of empathy (Cook, Jonikas, & Razzano, 1995; Wood & Wilson-Barnet, 1999) and other studies showed trainees rated the experience positively (Hayward, West, Green & Blank, 2005; Vijayakrishnan, Rutherford, Miller & Drummond, 2006).

Service user involvement has been cited as a key target in improving acute adult inpatient care provision, where individuals often present with challenging behaviours (Department of Health, 2002). Acute settings are frequently used by individuals with a diagnosis of Personality Disorder (PD), and it has been acknowledged that

> many clinicians…are reluctant to work with people with personality disorder because they believe that they have neither the skills, training or resources to provide an adequate service (Department of Health, 2003, p. 5).

The guidelines note that many service users thought that they should be engaged to help train professionals in order to promote greater understanding of this client group. Research has found that individuals with PD report considerable difficulties in their interaction and communication with mental health professionals (Barlow, Miller & Norton, 2007). One systematic review of UI in the delivery and evaluation of mental health services concluded that users with a history of severe disorders could effectively contribute to service improvement, although this may depend on adequate support, including training and payment (Simpson & House, 2002).

The majority of the UI literature to date has focused upon reporting audits or descriptive accounts of how service users have been involved in project work within various NHS Trusts. These accounts highlight that service user representatives are frequently involved in the training of mental health staff, including trainee psychiatrists, student psychiatric nurses and clinical psychologists in training (for review see Repper & Breeze, 2007). Despite this, it has not been possible to locate any accounts of training that service users themselves have received to prepare them for their role.

One qualitative study of UI found that mental health lecturers felt that inappropriate attributes of service users and the demand for high-level presentation skills were barriers to effective involvement (Felton and Stickley, 2004). More recent research has highlighted concerns over the objectivity, representativeness, and inappropriate personal disclosure of service users (Vijayakrishnan et al, 2006; Tait & Lester, 2005; Rutter, Maney, Weaver, Crawford & Fulop, 2004).

Livingston and Cooper (2004) argue that training for user-trainers is pivotal, because if individuals are unable to communicate effectively their message will be lost. Although the NHS Executive Mental Health Task Force User Group (1994) has published a training pack for mental health service users working as speakers or trainers, this guidance is dated, and it is impossible to gauge from the literature whether this material (or alternative training packages) are being utilised. Providing training for user-trainers can help increase their effectiveness and credibility, and ultimately improve recipients' experiences of UI. Adequate preparation for user-trainers is also vital to help ensure than UI is a safe experience for service user representatives.

The current paper has four key aims; 1) To describe the development of a service user reference group (CAST; Consultancy and Support Team), 2) To describe a unique training package delivered to CAST members in order to prepare them for their role, 3) To present the results of an evaluation of CAST members perceptions of the training package, and 4) Disseminate information about the type of projects and work undertaken by CAST members following their training. Implications for clinical practice and effective UI are also discussed.

Development of CAST

CAST was developed via a collaborative project between the NHS Trust's Consumer Advisor and a Consultant Clinical Psychologist at a local inpatient unit. One of the primary aims of CAST was to contribute to training aimed at improving staff attitudes towards services users with PD and to encourage a culture of acceptance towards this client group. Funding for the project was secured via a successful bid for service user monies from the South East Development Centre. It was also anticipated that CAST members would contribute to other projects within the locality after becoming more established. It was anticipated that an individual's membership of CAST would not exceed two years, with the aim of facilitating a return to meaningful occupation.

Potential CAST members were identified following recommendations from Clinical Psychologists in the locality, and were invited to attend an interview. Potential CAST members were expected to have a diagnosis of PD or complex needs, experience of using local inpatient services, and demonstrate that they met the national wellness criteria and were appropriately and effectively reducing their use of mental health services.

Of the six CAST members that formed the primary cohort, the group comprised one male and five females. The majority of the cohort (n = 4) had a diagnosis of Borderline Personality Disorder (BPD), and the remaining members (n = 2) had complex needs (excluding PD). Of the five CAST members that formed the secondary cohort, the group comprised one male and four females. The majority of the cohort (n = 4) had a diagnosis of BPD, and the remaining member (n = 1) had complex needs (excluding PD).

The Training Package

In order for CAST members to be seen as credible and professional, a unique training package was developed and jointly delivered by the creators of CAST. The training comprised eight 3-hour sessions over a period of approximately five months, and was delivered using a combination of didactic teaching, group work and role play. Sessions were focused around topics such as presentation skills and self-

disclosure (see Table 1), and were based on the assumption of participants having received no prior training in these areas.

Table 1. Core Topics Covered During CAST Training

- Making the commitment
- Communication skills
- Enhancing self-esteem/self-acceptance
- Self disclosure
- Presentation skills
- Assertiveness

Following the withdrawal of one individual from the first cohort, it was agreed that it was important to monitor the ongoing wellness of CAST members in future cohorts. Consequently the second cohort of CAST members were asked to rate their subjective level of wellness at the beginning and end of each training session using an idiosyncratic 10-point Likert scale.

Given the experimental nature of the training package, it was felt that future evaluation of the training would be important. Therefore participants in both cohorts completed a number of pre and post training outcome measures (see Table 2).

Table 2. Pre and Post Training Outcome Measures Used

- Service user Representative Group Questionnaire: SURG-Q (Cowdrill, unpublished)
- Robson Self-Concept Questionnaire: RSCQ (Robson, 1989)
- Inventory of Interpersonal Problems – Short Form: IIP.32: IIP (Barkham, Hardy & Startup, 1986)
- Assertiveness Scale for Adolescents: ASA (Lee, Hallberg, Slemon & Haase, 1985; Revised for the purpose of this study)

As can be seen in Table 2, the outcome measures comprised four different self-report measures to assess perceived levels of confidence, competence, assertiveness, interpersonal problems and self-esteem. The version of the ASA was developed specifically for the CAST evaluation, which involved minimal changes to the vignettes to make situations more relevant to the adult population. This revised version was preferred to other assertiveness scales because it utilises vignettes. The SURG-Q is an 11-item self-report questionnaire, which was developed by one of the creators of CAST to measure perceived levels of competency and confidence to deliver training to mental health professionals. Higher scores on a 5-point Likert scale indicate greater levels of perceived confidence/competence with a maximum score of 44.

Due to the small number participants and low completion rate of outcome measures it was not possible to conduct reliable quantitative pre and post training analysis.

However the pre-training outcome measure scores for the six participants who were interviewed are shown in Table 3.

Table 3. Raw Participant Questionnaire Scores, with Means and Standard Deviations

Participant Number	SURG-Q	ASA	IIP	RSCQ
1	31	17	14	95
2	26	11	19	65
3	32	13	15	143
4	24	14	22	112
5	27	10	37	89
6	31	19	29	119
Mean Score	**28.5**	**14**	**22.67**	**103.83**
Standard Deviation	**3.27**	**3.46**	**26.97**	**8.87**
Range	**8**	**9**	**23**	**78**

As can be seen from Table 3, participants' mean scores on the SURG-Q indicated a moderate level of perceived confidence and competence. Mean scores on the ASA, RSCQ and IIP indicated low levels of assertiveness, self-esteem and interpersonal difficulties, respectively. It should be noted that participant number 3 self-reported higher levels of self-esteem than the other participants and this is likely to have disproportionately affected the mean RSCQ score.

Evaluation of CAST Members' Perception of the Training Package

Method

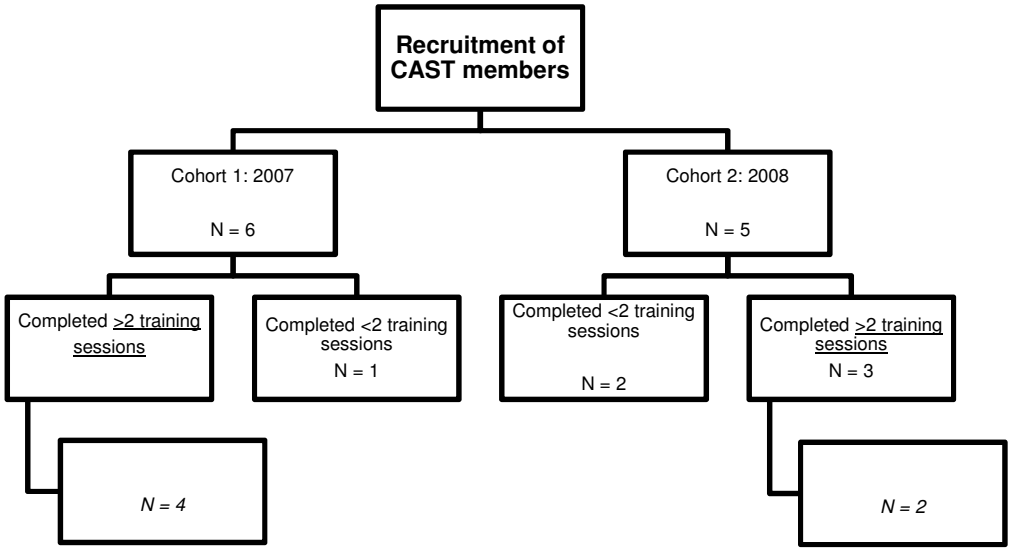
The evaluation of the CAST training was conducted as a Small Scale Research Project as part of the author's clinical psychology training, therefore ethical approval was gained from the University ethics committee.

Semi-structured interviews were selected as the most appropriate mode of investigation to gain in-depth feedback on the perceived efficacy of the training package, and areas for improvement. Due to the small number of participants it was not viable to conduct rigorous or reliable thematic content analysis on the qualitative data. The current paper presents an analysis of participant comments within a service evaluation of the CAST training package, utilising the structured process of identifying themes described by Braun and Clarke (2006).

Participants

Individuals who had attended at least two training sessions were invited to take part in the evaluation (n = 10), and six participants attended for an interview (denoted in italics; see Table 4).

Table 4. Summary of recruitment, training and evaluation participation of CAST members



Demographic information about the six participants that consented to take part in the evaluation was obtained from the participant information questionnaire. Four of the participants were female and two were male, aged between 35 - 44. Four participants were currently using mental health services and all were employed in either a paid or voluntary capacity (excluding their employment as CAST members). The majority had received a diagnosis of BPD and/or depression, and had spent a mean length of twenty-three months in psychological therapy. The majority also had experience of receiving Dialectical Behaviour Therapy (DBT).

Procedure

CAST members were contacted via email or telephone inviting them to take part in the evaluation, and a suitable time and date to conduct the interview was agreed. At the interview stage participants were asked to sign a consent form and complete a participant information questionnaire to obtain demographic information.

Individual interviews were carried out with the participants using an informal, conversational style as described by Patton (1987). This was felt to be especially important in order to allow rapport to be established with participants and facilitate honest feedback. Following discussion with the creators of CAST about the type of information they wanted to gain from the evaluation a list of five interview questions were constructed as an interview guide (see Table 5). All interviewees were asked the same five questions, which were then followed up with more specific questions depending on their responses. There was also an opportunity for participants to raise any other important issues or comments.

Table 5. Interview Questions

- What do you feel that you have brought to training?
- What do you feel that you have taken away from training?
- What has been most helpful about the training?
- What has been least helpful about the training?
- Are there any ways that the training could be improved?

Individual interviews were facilitated by the researcher, and were tape recorded and transcribed verbatim to enable thematic content analysis to be conducted on the material. All participants were given a debriefing statement after the interview and offered a copy of the final report.

Data Analysis

It was possible to identify two main themes of "CAST as successful" and "CAST as unsuccessful", and six sub-themes emerged; personal and professional gains, importance of team work, satisfaction with teaching, lack of organisation, difficulties with communication and recruitment issues.

Personal and Professional Gains

In response to the interview questions "What do you feel you took away from training?" and "What has been most helpful about training?" all participants said they had gained either personally or professionally from the CAST training. Participants described gaining a sense of utility from their involvement in CAST, and a subsequent sense of satisfaction by feeling they were able to contribute to the improvement of patient experience for others.

> I'm getting a sense of utility…of feeling like I might have a useful purpose...rather than just sitting there niggling away and stagnating.

Another participant talked of her sense of euphoria after perceiving a positive change in staff attitudes towards BPD after contributing to staff training:

> From the very first session when we sat down you could really feel that people didn't want to be in the room and at the end…they were sitting up and they were listening to what we had to say…and to have that kind of impact straight away…was enormous.

Many participants felt that CAST had acted as a catalyst for a return to employment, either through increasing their level of confidence and self-esteem or via the contacts they had made with professionals during the process of CAST training:

> I'm working now, and I know that if I hadn't been in CAST I wouldn't have had the experiences I have had, I wouldn't have met the people I've met and that's been instrumental in me getting the job that I've got.

Importance of Team work

A strong theme about the importance of team work emerged, and how effective team working was viewed as a key factor in the success of the CAST training:

> I think it's quite important to be able to work as part of a team, especially bearing in mind the type of illnesses people are recovering from, you know, if one particular person is going through a rough patch, you want to be able to rely on a team mate.

There was a lack of agreement amongst team members about whether homogeneity amongst team members had a positive or negative effect upon effective team working. While most participants felt it was important to have CAST members with a range of different mental health problems and experiences, it was also acknowledged that the majority of members had been diagnosed with BPD which may have left other members feeling excluded:

> I think it's quite difficult for people who haven't done DBT in a CAST group, because…people…are talking about things in a DBT language which is like Swahili to people to someone who doesn't know DBT.

When questioned further, participants agreed that characteristics of a "good" team member were: a willingness to participate, hard working and objective. One participant also described how they felt that having such attributes contributed to the success of training:

> I think one of the things I brought was my willingness to participate…I didn't want to participate but I forced myself, and I think that helped, possibly encouraged some of the others to participate a bit more.

Satisfaction with Teaching

There was unanimous agreement among the participant's that the quality of the training package very high. None of the participants felt that there should be any changes to the individual session topics, and the sessions on self disclosure and presentation skills were considered to be the most valuable:

> I think I wouldn't have been interested in it if there wasn't the training…I think that's very important that you are taken seriously, so you don't just become the token service user group.

> I think the one that had quite an impact on me was the level of disclosure, knowing what your boundaries are…I think that's a very important part of the training…you can get across the impact without going into …minute details.

All participants reported a very high level of satisfaction with the method of the delivery of training, favouring a mix of role-play, didactic teaching and more experiential methods of teaching e.g. mindfulness exercises. Participants felt that the facilitators created an informal and open atmosphere during the training sessions, and this was instrumental in participants feeling able to honestly rate their current level of wellness at the sessions:

> It was very easy going and it was very enjoyable, but most of all we were listened to.
>
> Seeing them [the facilitators] so motivated and inspiring and enthusiastic, that was really nice…and…I felt quite secure in training, and I felt that if I did have a problem in training I could talk about that.

None of the members reported discontent with being asked to rate their wellness, and in fact felt reassured that their readiness for CAST was being continually monitored in an open and frank way. With regards to teaching methods, experiential exercises were favoured by participants:

> The role plays were brilliant. I hate role plays…however I've learnt a lot from doing that.

Lack of Organisation

One of the key ways that participants felt the training could be improved was via better organisation outside of the training sessions. It was felt that that having an identified contact person who was able to act as a "hub" for managing the day-to-day running of CAST (e.g. administrative duties) would have been helpful. Participants acknowledged that the creators of CAST had other responsibilities but felt that more staff were required to facilitate the successful progression and organisation of CAST:

> If our details and specialism's were on the computer and a request came through then we could be contacted, that would be so much better, there could be a database of members, what they are doing, what they want to do, what is being done, and you could find the most appropriate person for each thing.
>
> I think it's still in such early stages that the publicity and organisation haven't kicked off and I think if CAST is going to achieve what we can achieve things need to change.

Some of the participants felt that the lack of organisation had the potential to negatively affect the motivation and impetus of individual members and the whole group, respectively.

Difficulties with Communication

A strong theme emerged that communication between the facilitators and CAST members could be improved, especially at the beginning and end of training. Members felt that at the outset of training they were not clear about what was expected of them and what tasks they might be expected to undertake:

> I still to this day am not fully conversant with what is expected of me and the ironic thing is, I have this idea in my head, and it appealed to me but whether it's just me personally or the type of person I am, I would have preferred much more information than I got.

Members also felt that they experienced feelings of "anti-climax" at the end of training, because they did not feel that the intensity and volume of assignments had been adequately communicated. As one participant commented:

> I felt the hardest thing was when we finished our CAST training we were sat in limbo, there was nothing to say this was coming, this is what we were likely to be doing.

Participants felt that problems with communication could be addressed by increased verbal and written communication about their role expectations at the selection stage. Participants' frustration about their role expectations are unsurprising in light of the embryonic stage of CAST, which will undoubtedly improve with future cohorts.

Recruitment Issues

A final theme that emerged was surrounding recruitment issues, and closely linked problems with the identification of potential members, exclusion criteria and selection methods. One participant expressed concern that inappropriate recommendations for CAST membership might be received if referrers are not clear about the purpose and role of CAST:

> I think the people they get their referrals from need to have a clearer idea of what the criteria is….it's not a support group.

Participants articulated the need for a comprehensive and thorough assessment of suitability to enter into the CAST training. Several participants expressed the opinion that asking interviewees to participate in a group exercise, presentation or role play as part of the selection procedure may help assess suitability and interpersonal functioning more rigorously. All participants agreed that having current CAST members attending selection procedures was helpful and should continue with future cohort selection.

There was disagreement about whether current use of mental health services should act as exclusion criteria from membership of CAST. The idea of readiness for training was cited as a key component for selection, which appeared to have strong overlaps with an individual's willingness to participate in training activities, rather than be associated with current use of mental health services:

> In some ways training is a little test, if you can't do that then you're probably not ready for CAST.

Other than introducing more interactive selection methods that might highlight a reluctance to participate in training activities such as role play, participants were unsure of how to improve the selection of CAST members. Several participants felt that exclusion criteria were a sensitive issue, and readiness for training was a complex and dynamic concept that was not easily measured. Concern was expressed that unless readiness for training was assessed on a case-by-case basis, suitable members might be unnecessarily excluded or vice versa.

Irrespective of whether participants were currently active members of CAST, all felt that the training process had been a challenging yet positive experience.

Discussion

It appears that the CAST training was effective in enabling members to feel confident and competent to deliver training to mental health professionals, and effectively contribute to UI. All participants expressed high levels of satisfaction with

the atmosphere created during the training sessions, individual topic sessions, and methods of delivery. However barriers to the success of the training package were identified as poor organisation, communication about the remit and scope of CAST, and a need to improve selection procedures of CAST members.

The analysis of participants' comments about the CAST training revealed two key issues that are particularly important for effective UI. The first of these is the complexity surrounding appropriate recruitment of suitable service user representatives. It is very difficult to gauge from the literature what percentage of service user groups incorporates a rigorous recruitment procedure to select members. Arguably the diversity in UI implementation makes it difficult to expect potential service user representatives to meet standardised criteria. However the current evaluation suggests that willingness to participate may be a core pre-requisite for service user representatives, which may be best assessed via experiential selection methods e.g. role-play. Careful consideration of participants' motivation, current level of wellness and training needs were a key component to the success of the CAST project, to protect the mental health of the user-trainers and ensure that the training needs of staff were met. On a broader level, careful selection and training of members of UI groups can help to challenge concerns about inappropriate attributes of user-trainers and help promote professionalism and credibility of UI.

The second key issue arising from the evaluation was the impact that management can have upon the success of UI, which encompasses administrative support, funding, and facilitating the development of a cohesive and supportive team atmosphere. The team atmosphere within CAST was viewed as a key aspect of the success of training, especially the candid way that sensitive issues such as wellness-monitoring were dealt with. However, it was clear that limited funding – and subsequent practical support – had a frustrating impact upon individuals, as noted by previous reviews of UI (Rutter et al, 2004; Wallcraft, 2003). Feedback from participants suggests that the contribution of CAST members towards various projects (including training for mental health staff) was positively received and highly valued. Further research into the efficacy of user-led training is essential, especially within the current climate of evidence-based practice. Further research would also strengthen applications for practical or financial support from NHS Trusts to ensure sustainability of effective UI, as opposed to discreet or temporary projects.

The analysis of participants' feedback has identified several strengths of the CAST training package (see Table 6), which may be of use to other organisations considering implementing similar training packages for user groups.

Table 6. Summary of Participants' Feedback about the Key Strengths of the Training Package

- Informal and enthusiastic style of facilitators
- Regular monitoring of wellness within training sessions
- Feeling listened to and respected (avoiding tokenism)
- Careful and relevant selection of session topics
- Facilitation of a strong ethos of mutual support and team working
- Effective teaching methods

CAST: The Future

Following the completion of the training package, CAST members have been successfully involved in a variety of projects, in addition to the key project of contributing to PD training for mental health professionals. Such projects include attending Trust-wide DBT meetings, presenting at regional PD conferences, and contributing to interview panels for mental health staff and teaching for Trainee Clinical Psychologists within the locality. The successful contribution of CAST members to this diverse range of projects – and the subsequent demand for high level communication skills – demonstrates itself the effectiveness of the training package.

As highlighted in the feedback from participants, many CAST members have successfully returned to meaningful employment after less than two years of membership. The current findings will be able to contribute towards improving the forthcoming recruitment of another cohort of CAST members to replace these members.

Conclusion

As noted by Campbell (2001), the debate around UI has largely shifted from "why" to "how" it should be incorporated successfully into the NHS. Many authors have summarised the key the barriers to UI (Bassett, Campbell & Anderson, 2006; Tait & Lester, 2005), but there is a disproportionate amount of literature about the factors associated with successful implementation, which is vital for the continued development of UI.

The current evaluation has highlighted that recruitment of appropriate service user representatives and providing adequate preparatory training for them are key aspects of "how" to implement UI. Livingstone & Cooper (2004) point out that universities are required to ensure teaching is of an adequate standard, and there is little literature to demonstrate how user-trainers are deemed to meet this standard. Providing training for service user representatives is vital to maximise the impact they can have on improving service delivery, and ensure the process is a safe one.

More robust research in the field of UI is greatly needed, and appears to be hampered by small sample sizes and lack of rigorous methodology. Research into the mechanisms by which recipients of UI projects perceive it as efficacious is needed, and could help user-trainers to communicate more effectively with their audiences. Comparative research into perceived efficacy and confidence to work as a user-trainer in service user groups with and without preparatory training would reinforce the need to provide adequate support and skills for service user groups like CAST.

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