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Perceptions of service user and carer involvement in healthcare education and impact on students’ knowledge and practice: a literature review

Angela Morgan
School of Health & Social Care, University of Teesside

Diana Jones
School of Health, Community and Education Studies, Northumbria University

Corresponding Author
Angela Morgan
Assistant Dean Learning and Teaching
School of Health & Social Care
University of Teesside
Borough Road
Middlesbrough
TS1 3BA

Telephone 01642 384915
Fax
e-mail A.Morgan@tees.ac.uk
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Abstract

Background
The involvement of service users in healthcare education has followed an increasing focus on patient-centred services. CETL4HealthNE, regional healthcare education collaboration, undertook a literature review to inform involvement strategies.

Objectives
To identify - approaches used to involve service users in healthcare education curricula; perceptions of key stakeholders; impact of involvement on students’ knowledge and skills, and the quality of care delivered.

Method
A structured search of the literature on service user involvement in Higher Education healthcare curricular activity was undertaken (July 2006-February 2007). Papers were screened and data extracted and synthesised according to the aspect of the curriculum enhanced by involvement and level of impact evaluation.

Results
Thirty papers addressed interventions in pre- and 11 in post-registration education. Thirty studies reported on evaluation. Students and service users both benefited from service user involvement in health care programmes. There was limited evidence that involvement changed behaviour in practice or significantly benefited the recipient of care.

Conclusions
Further consideration needs to be given to evaluation methodologies. A strategic, incremental approach to enhancing service user involvement is recommended, with preparation of service users for their role and students for service user involvement.

Key Words: service user and carer, curriculum, involvement, healthcare, education
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Introduction

The drive to involve service users and carers in the design, delivery, assessment and evaluation of healthcare professional education and continuing professional development programmes has come from the increasing focus on patient-centred health policy. The Community Health Councils, set up in 1974, heralded consumer orientation in health care (Andersson et al 2006). The rhetoric in key Department of Health (DoH) policy documents such as Working for Patients (1989), the Patients’ Charter (1991), the NHS & Community Care Act (1991), and changes in GP contracts at that time, began to reflect user control, rights, perspectives and evaluations. Professional healthcare regulatory bodies recognised the need for good communication skills and attitudes towards patients (General Medical Council 1993), and there was a call for healthcare consumers to be involved in the planning and delivery of professional education (English National Board 1996).

The policy drive continued to place importance on demonstrable improvements in patient and carer experience (DoH 1997). Patient partnership was made central to the work of the NHS and other bodies, including those training healthcare professionals (DoH 1999), with patients having more say in how healthcare was provided in their localities (DoH 2000; DoH 2001). There was recognition amongst academics in the field of mental health in higher education that if partnerships with service users and carers were going to be the key feature of service delivery, they should also be central to mental health education, and that this would increasingly be an expectation of professional bodies and commissioners (Tew et al 2004). Their good practice guide was accompanied by the National Continuous Quality...
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Improvement Tool (Brooker & Curran 2006) in an attempt to embed involvement in the routine processes of management of mental health education.

In a review of the literature on user and carer involvement in the training and education of health professionals, Repper & Breeze (2004, 2007) comment that consumer involvement seems to be based on the assumption that it will lead to practice that is more aligned to consumers’ expectations. However they found little evidence that studies were examining this, focusing, as they did, mainly on process rather than outcome, in common with much published educational research (Murray 2002). ‘Principles for Practice’ (Trent Strategic Health Authority 2005), a resource to help healthcare educators to engage with service users, reinforced the assumption that it is “about involvement for improvement of the experience of people using health and social care services.” This theme was taken up again in the Skills for Health (2006) leaflet ‘You can influence the quality of healthcare education’, in the strap line ‘Influence today …improve tomorrow’. However, measuring the impact of user involvement is complicated by the lack of a clear understanding of the concept of user involvement practically and ideologically in the current welfare framework (Cowden & Singh 2007).

Building on a policy emphasis on personalised care and patient choice (DoH 2004; DoH 2005), local people are now being empowered to provide the major drive for service improvement (DoH 2006a). NHS organisations have been given advice on the principles of reimbursing and paying for involvement activities (DoH 2006b). There is a need for all higher education institutions educating healthcare students to know how to involve safely and effectively. Skills for Health (the organisation now
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responsible for the quality assurance arrangement for health professional programmes), via the Interim Standards (Skills for Health 2007), require evidence of service user involvement in both education as well as service provision. Additionally, the Nursing and Midwifery Council (HLSP/NMC 2006) are requiring Universities to involve a service user as a panel member during the approval process for pre-registration nursing programmes.

Involvement of people with experience\(^1\) in educational provision is being promoted by one of the work strands of the Centre for Excellence in Health Professional Education in the North East of England (CETL4HealthNE). This is a regional collaboration funded by the Higher Education Funding Council for England (HEFCE) that is undertaking a 5 year programme of work (2004-2009) which aims ‘to foster curriculum development for employability in the modernised health care service’. (CETL4HealthNE 2007). The CETL partners include the five North East Universities, the North East Strategic Health Authority and three NHS Organisations. The mix of CETL4HealthNE partners enables knowledge gained in practice to influence education and vice versa, which is of particular relevance in relation to the longer history of service user involvement in practice.

The People with Experience – User Involvement (PWE) work strand aims to mainstream the involvement of people with experience in the development, delivery and assessment of curriculum in order to facilitate the preparation of health care

\(^1\) The term ‘people with experience’ emerged from a previous study undertaken in the region that involved service users in the development of an inter-professional learning activity. Service users in that project described themselves as ‘people with experience’ and preferred to be referred to as such.
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professionals who will routinely involve users and their carers in decisions regarding their health and social care in order to meet their individual needs and the needs of their communities. This review was undertaken to inform the development of regional strategies to enhance involvement with a wide range of healthcare professionals to match the CETL student profile, with a particular focus on the outcomes of involvement interventions on the knowledge, skills, attitudes and behaviours of students.

The aims of the review were to identify:

1. models, approaches and strategies used to involve service users in the design, delivery, assessment and evaluation of healthcare education curricula
2. the perceptions of key stakeholders about user and carer involvement in healthcare education
3. the impact of involvement in education on students’ knowledge and skills
4. the impact of involvement in education on the quality of care received by the service user.

Review Methodology

A structured literature strategy was developed by the CETL4HealthNE PWE working group, which includes service user and carer representatives, in conjunction with two experienced Information Professionals, one of whom subsequently implemented the search.
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Search Strategy

The online databases searched included AMED, Assia, BNI, British Education Index, CINAHL, Cochrane Library, Embase, Index to Theses, Medline, National Research Register, OTDbase, PEDRO, Proquest, Psycinfo, Scopus, Social Care Online, ZETOC. The British Library Catalogue was also searched and Internet sources included Subject gateways eg NMAP, OMNI, SOSIG, Google, Google Scholar, likely websites e.g. Department of Health, National Library for Health, and INVOLVE.

The framework for the search strategy is set out in Table 1; however the precise search strategy for each information source differed according to the available search facilities. The groups were combined as follows:

1 and 2a and 3 and 4
2b and 3 and 4
1 and 2a and 3
2b and 3
2b and 3 and 4

Where searching allowed all terms were mapped to subject index and exploded, all were searched as keywords with truncation, and all combined with OR.

The search was carried out between July 2006 and February 2007 and references were exported into a RefWorks database. After removal of duplicates 243 references were retrieved.
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Inclusion Criteria

The abstracts (where available) and papers (where no abstract was available) were screened against all of the following inclusion criteria:

1. The paper describes a strategy, model or approach to the involvement of service users or carers.
2. The involvement relates to programme commissioning, curriculum development, delivery, assessment, evaluation or recruitment and selection of students in a Higher Education setting in the UK.
3. The programme relates to students involved in CETL4HealthNE programmes (medicine, dentistry, speech and language therapy, nursing, occupational therapy, radiography, physiotherapy, midwifery, healthcare foundation degrees).

The screening was done predominantly by AM, although any that were not straightforward were discussed with DJ and a joint decision made.

Data Extraction and Synthesis

Relevant data were extracted from the included papers using specifically designed data extraction tools based on Critical Appraisal Skills Programme (2007) guidelines. The papers were initially tabulated according to the aspect of the programme the involvement activity related to e.g. curriculum development, delivery, assessment etc. Kirkpatrick’s (1967) framework for evaluation of interventions was modified (Table 2) to enable synthesis of impact. This framework has been modified in other evaluation studies (Carpenter et al, 2006). Screening and data extraction were carried out...
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predominantly by one author (AM) but in close consultation with the second author and areas of uncertainty were clarified and agreements reached. Both authors agreed on the allocation of papers to Kirkpatrick's levels.

Limitations to Review Methodology

Whilst the search strategy carried out was comprehensive and rigorous there is no guarantee that all studies have been located. The search focused on published literature and did not attempt to obtain unpublished studies. A lack of resources precluded detailed cross checking of references cited in every paper.

Findings a – Overview of the studies and their methodological quality

In total 243 references were retrieved. The main reasons that papers were excluded were as follows: no involvement intervention; anecdotal or journalistic style; conference proceeding; non United Kingdom study; unpublished thesis; unpublished research; learning materials; webpage. Forty four papers remained. It was subsequently found that three studies had two papers reporting different stages or aspects of a single evaluation (Ikkos 2003 & 2005; Barnes et al 2000 & 2006; Forrest et al 2004 Part 1 & 2). Each of these is reported in this review as one study, leaving 41 included studies. Each included study is referred to using an identifying number shown in the Tables 3-7 and the full reference for each number is given at the end. Thirty papers addressed involvement interventions in pre-registration programmes and 11 in post-registration. Ten studies did not report any formal evaluation, twenty-four reported level 1 evaluation, four level 2, and one each at levels 3 and 4.
Design and Methodological Quality of the Studies

Tables 3-7 show brief details of the methods used to evaluate the involvement interventions. The level 1 evaluations predominantly used qualitative methods and/or routine teaching evaluation questionnaires or small scale surveys. Within these papers, specific details of the methods used were often sparse, making judgements in relation to the academic rigour of the studies difficult. However, during the synthesis of the studies, several common themes emerged which gives some confidence that the findings, whilst highly context specific, may have some wider applicability.

The level 2, 3 and 4 studies attempted more rigorous designs in order to establish objective assessments of changes in knowledge, attitudes and behaviour. The methodological qualities of these studies is discussed individually and threats to validity and reliability are inevitably present in all of them which highlights the difficulty in establishing cause and effect relationships following educational interventions (Murray 2002).

Findings b – Results

Models, Approaches and Strategies for Involvement

Tables 3-7 give a summary of the papers under the highest evaluation level, although some papers contained several levels. Papers 1-11 (Table 3) referred to strategies to enhance the involvement of users in curriculum design using a variety of methods.
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Papers 12-38 (Table 4) focused on strategies to enhance involvement in curriculum delivery including involvement in classroom activities, practice-based interventions, skills workshops, the development of learning materials and the appointment of a service user to an academic post.

Only one paper (39, Table 5) had user involvement in assessment as its main focus, although papers 20 & 28 mention the involvement of users in giving formative feedback. One paper (40, Table 6) reported on the involvement of users in programme evaluation. The remaining paper (41, Table 7), the most embedded example of user involvement, reported on user involvement in all aspects of the programme.

Level 1a – Students’ Perceptions

Overall, students’ perceptions of user involvement were generally positive. Satisfaction scales were used in papers 13, 18 & 22 and sessions were rated highly by students. Although satisfaction scores were acceptable, some sessions had slightly lower ratings when taught by service users rather than doctors (36) and a ‘simulated patient’ received higher scores than a ‘real patient’ in one study (34). Students found the experience of user involvement rewarding and felt that it had a positive impact (15, 25, & 27) and it enhanced their understanding and promoted learning about the user’s perspective (15, 16, 17, 18 & 26). Students felt privileged to hear users’ stories (31) and found user-centred learning materials interesting and motivating (12). Students agreed with user-centred values (41) and reported a desire to change services (22), enhanced communication skills (21), increased confidence
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when talking to patients with serious illnesses, and an insight into multi-disciplinary team working and patients’ problems (24).

Whilst no distressing consequences were noted, in one study (33) some students reported feeling embarrassed (16), emotionally challenged when the patient they are visiting died (24), anxious (25) and expressed concerns about potential discomfort (37), although the latter were less evident as the involvement continued. User contributions were seen as antagonistic by some students (41) whilst others said that there was a need for a more balanced expression of opinion in a mutually supportive learning environment (18). Some students challenged (22) or were concerned about (37) the representativeness of service users and some had mixed views on the helpfulness of feedback on their assessed work and did not think that they would make changes to their practice based on it (39).

Level 1b – Service Users’ Perceptions

The studies reported overwhelming benefits for service users and gave an insight into the reasons why they became involved. None of the studies reported any negative effects. Some service users enjoyed contributing to better inter-professional relationships (12) and others found the experience rewarding and enjoyable (28 & 12). They found students to be non-judgemental and enthusiastic (33) and felt that their contributions were valued (21). Some viewed themselves as experts in their own condition (30), enjoyed being able to use their illness in a positive way (36) and gained satisfaction from helping students to learn (30).
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Users became involved for mainly altruistic reasons, wanting to enhance the practice of future doctors (13), offer real life experience (23), improve (19) or put something back (28) into the health service or community (14). Barriers to involvement noted in one study (14) were embarrassment and anxiety about students accessing medical records. More guidance and time to tell their stories would have been welcomed by some (31). Whilst service users in one study (11) reported satisfaction with the practical issues of involvement (e.g. timing, venue), there were some reported difficulties with payments and the level of support and training given for the role.

Many studies reported enhanced personal development. Some carers reported that involvement gave their caring experiences meaning and value and service users reported enhanced confidence (11, 20, 35 & 39), feelings of self-esteem and self-worth (33 & 36), and empowerment (17 & 21). The experience was found to be cathartic in two studies (16 & 17) and service users enjoyed being listened to (19). For several it improved their knowledge of their condition (21 & 35), their medication (28) and the services available (39) and made them more questioning of health professionals (28). For others, their insight into their circumstances was enhanced through the development of a coherent narrative during the involvement activity (33). Relief from social isolation (28 & 30) and developing new friendships (39) were also important benefits.

**Level 1c – Staff Perceptions**

Very few studies reported the views of staff in any substantial way. Very little resistance from tutors was noted in one study (17) and the inter-professional
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facilitators in another study (15) found the experience rewarding. Some respondents in one study (11) expressed concerns about the representativeness of users involved in a strategy development group and some concerns were noted regarding getting wider involvement from all staff.

Level 2 - Modification of Attitudes/Acquisition of Knowledge and Skills

Four studies (34-37) attempted to identify changes in measured attitudes, skills and knowledge as a result of an involvement activity. One study (36) carried out a randomised controlled trial and two (34 & 35) used a quasi-experimental approach where random allocation was not present. The fourth study used a mainly qualitative comparison.

In study 36, where students received skills training from a Patient Educator (PE) or a consultant, the main dependent variable was skills in hand and knee examination, which was operationalised using hand and knee Objective Structured Clinical Examination (OSCE) stations. The researchers state that the study was adequately powered and good attempts were made to control extraneous variables. The study found no significant differences in mean hand or knee OSCE scores between the two groups. Although involvement of PEs did not lead to enhanced student skills compared to the consultant taught group, the researchers concluded that PEs were just as effective at teaching hand and knee examination skills as consultants and were less costly to employ.
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Study 34 made comparisons between students who were taught history-taking skills (relating to alcohol use/misuse) by either a real patient, a simulated patient (actor) or a videotape of the simulated patient. The dependent variables included a measure of knowledge (MCQ test) and two measures of attitude derived from previous students, but with no information relating to their validity and reliability. No significant differences were noted between groups on the MCQ test and attitude scores. However, the non-random method of allocation to groups threatens the validity of the findings and a type II error (wrongly accepting the null hypothesis) cannot be ruled out as no power analysis was reported.

Similar methodological weaknesses are also present in study 35 which allocated alternate groups of students to two workshops facilitated either by a Patient Partner (PP) or clinically based doctor. Performance in an OSCE station was used to measure the effect of the PP teaching on students’ history taking skills. There were no statistically significant differences in the scores between the two groups of students, although the overall OSCE scores were on average 2 marks higher for the students receiving PP teaching. Students also completed a before and after self-assessment of their consultation skills and no significant differences were found between the two groups, apart from skills in eliciting information. The PP group post teaching scores were slightly higher (3.3 versus 2.9). Although statistically significant (p=0.03) the educational relevance of this is probably limited. Drawing any conclusions from this study is difficult in light of threats to validity, including non-random allocation to groups and non-standard treatment of both groups.
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In the remaining level 2 study (37) students either experienced user involvement in classroom activities in term 6 (n=27) or term 7 (n=25). A tool for measuring user-centeredness was developed from a video of a user assessment. This was subsequently used as a framework for a mainly qualitative evaluation. The study concluded that the first group to experience user involvement demonstrated a more user-centred approach to mental health assessment when compared to the comparison group. The differences levelled out when the comparison group experienced user involvement although the first group remained slightly higher. The authors conclude that user involvement earlier in the programme is more effective in influencing learning, although they acknowledge that the first group had longer exposure to user involvement than the second group. It is difficult to judge the methodological quality of this study as the paper reports only some aspects of the methods and results. However, whilst the results may indicate a trend, there is insufficient methodological rigour (as acknowledged by the researchers) to produce definitive findings.

Whilst study 38 contained level 3 outcomes it also addressed some level 2 outcomes. This was a randomised controlled trial to evaluate the immediate effects of the participation of patients with cancer on the attitudes of undergraduate medical students receiving an interview skills training programme, and measured the effect on students’ attitudes and interview performance 2 years later. The students received communication skills training with participation by patients with cancer or by patients with other diagnoses. Internal validity was enhanced by using a standardised teaching protocol for both groups and the random allocation achieved two comparable groups therefore controlling confounding variables. The study found that
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at the end of the skills training students taught by patients with cancer were more likely to consider the ability to listen to patients as being extremely important, to feel more strongly that trust is essential and to agree that the attitude of patients to their disease can affect their illness. At the two year follow-up of 54 students, the need for clinical decisions to reflect patients’ wishes were considered more important by students originally taught by cancer patients.

Level 3 - Change in behaviour

Only one study (38) attempted to find out if the newly acquired skills, knowledge and attitudes were evident in the everyday practice of the student as assessed by an observer (see above section for details of the methodology). In the interview skills analysis which measured behaviour in the practice setting, students taught by cancer patients had better ratings in a real life interview in terms of responding empathetically, showing concern and assessing the impact of symptoms on the patient’s life. The authors conclude that involving patients with cancer in an interview skills course is more likely to result in students with better communication skills than those taught by patients with other diagnoses. However, the methodological quality of the two year follow-up is questionable, as there are potential mortality and history effects i.e. students may have been exposed to different experiences in the intervening two years which could provide an alternative explanation for any differences seen.

Level 4 – Benefits to Service Users
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Only one paper (41) attempted to assess if there was a tangible benefit to the health and well-being of service users who received care from students exposed to user involvement. The level 4 aspect of this paper involved a comparison between the professionals participating in the programmes (n=143) and professionals from other areas who had not done the programme (n=62). Further detail of this methodology is given in Carpenter (2006) where an assurance is given that the comparison area is similar in all respects to the study area apart from access to the programme. However, it is acknowledged that there were inherent differences between the study and comparison groups which may impact on the validity of the study.

A user-defined tool was developed to measure quality of care outcomes and, in addition, standardised measures of mental health, social functioning and quality of life outcomes were administered. The outcomes for the user-defined questionnaire were positive for both groups. Similar proportions in each group stated that students had involved them in their care as much as they would like. Significantly greater proportions of service users in the study group reported that students had asked whether they wanted a carer or member of their family involved in care than in the comparison group. There was also greater improvement in social functioning for the programme group than the comparison group. The researchers stated that this difference may be due to the emphasis in the programme on involving family carers. However, an alternative conclusion might be that the differences are due to inherent differences between the study and comparison groups. This again highlights the methodological challenges in designing an evaluation study to assess the impact of educational interventions at the higher levels.
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Discussion

It is clear from the review that involvement of service users in the education of health professionals is gaining momentum. The review revealed that several universities have developed specific strategies to enhance service user involvement and have made these available via their web sites. Links to web sites that were found during the review are available via the CETL4HealthNE (2007) website. Likewise, the formation of networks such as the Professional Education Public Involvement UK Network (PEPIN 2007) and the Developers of User and Carer Involvement in Education and Training network (DUCIE 2007) is further evidence of this momentum. Unfortunately, only one paper in the review evaluated a service user involvement strategy and there were no evaluations published regarding the development worker role.

The majority of the papers reviewed related to the education of doctors (14) or nurses (19) with the professions allied to medicine being under represented. As identified in the review published by Repper & Breeze (2007), many of the interventions (13 papers in total) related to the field of mental health across the professions of nursing (10) and medicine (3).

Initiatives to enhance involvement in curriculum delivery were most prevalent, although several described involvement in curriculum development. There were no papers that mentioned involvement in the recruitment and selection of students and only one that focused specifically on the assessment of students. There were two papers that did focus on service user involvement in assessment of students that
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were excluded from the review because they were non-UK studies (Greco et al 2001 and O’Keefe et al 2001). A UK based paper published after the cut-off date (Kilminster et al 2007) concluded that simulated patient assessment of medical students was reliable and increased the validity of the student assessment overall.

There was also limited evidence of involvement of service users in the practice setting and since a significant proportion of health care programmes are facilitated in the practice setting this is a significant gap.

Two papers referred to the appointment of service users to academic posts and the success of these posts appears debateable. Paper 41 reported that although commitment to their comprehensive approach to service user involvement did not diminish, service user team member posts were not replaced when they were vacant. A follow up to paper 29, published after the cut-off date (Simons et al 2007) reported that the post was not well integrated in the team in terms of normal educational activities and processes. Some of the educators demonstrated resistance to the post and it was concluded that strategies to avoid stigmatisation and discrimination were not always effective. This may be explained by the findings of Felton & Stickley (2004) who explored mental health nursing lecturers’ experiences and perceptions of involving service users in education. They concluded that an inequality of power between service users and educationalists was apparent throughout the discussion. It could be that when attempts are made redress this power differential by the appointment of service user academics there are cultural barriers to its success. As these findings relate to a context where service user involvement has been more established (mental health nursing) it may be more realistic to recommend the
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adoption of an incremental approach until there is a greater readiness for change in terms of the culture.

Also relating to readiness for service user involvement, the evaluation of students’ perceptions suggest that, whilst students view service user contributions as being very valuable, they may benefit from being better prepared regarding what to expect. Likewise, enhanced recruitment processes and preparation of service users for their role may help to ensure that activities take place in a mutually supportive environment.

The majority of papers in this review did include some formal evaluation. The main exceptions were in papers that described service user involvement in curriculum design. Whilst these papers do demonstrate that involvement in activities did impact on the content of programmes, there were no attempts made to assess the impact that this had on students who subsequently completed the programme.

Those studies that included an evaluation mainly evaluated students and service users’ perceptions of their experience, with only a small number addressing educators’ views. The dissonance noted between service users’ views and those of students and educators validates the need to involve service users if their perspective is to be truly valued. A limited number of studies attempted higher levels of evaluation addressing the impact on students’ attitudes, knowledge, skills and behaviour and benefits to service users. Those studies evaluating at the higher levels did so by attempting some before and after comparisons or using some form of comparison group. The analysis of these studies has revealed the challenges and
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difficulties that researchers face when attempting to design and carry out studies to establish ‘cause and effect’ relationships.

Conclusion

This review has found that students are generally very positive about service user involvement in their programmes and reported positive effects on their learning. Some service users’ contributions were seen as antagonistic and the representativeness of service users was challenged by some students. Service users reported cathartic effects and other benefits resulting from their involvement included enhanced confidence, self-esteem and feelings of empowerment. There were no reports of any negative effects for service users. Very few studies reported on educators’ views on specific involvement activities although representativeness was an issue in one study. Preparation of students and service users for involvement activities is necessary to ensure that they take place in a mutually supportive environment.

There is limited evidence that service user involvement in education does impact on the knowledge and skills students. Only one study demonstrated some changes in attitudes following involvement by patients with cancer. The other studies generally found no change, including when compared with teaching by faculty. However, one study reported a more user-centred approach in assessment but the evaluation revealed some methodological flaws. Likewise, there were threats to reliability and validity in a study that attempted to demonstrate a change in behaviour in practice that reported enhanced communication skills. There is also limited evidence that
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involvement activities make a tangible difference to the health and well-being of service users who receive care from students exposed to user involvement in the curriculum. Whilst there was some improvement in health outcomes reported in the one study that addressed this, the validity of the comparisons made in this study is challenged.

The review demonstrated that service user involvement in recruitment, selection and assessment of students is limited and further thought needs to be given to involvement in activities in the practice setting. It has also identified the challenges faced when attempts are made to demonstrate impact of involvement activities on students’ behaviour and service user health and well-being and further consideration needs to be given to this if the real benefits to service users are to be demonstrated.
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Practice Points

- Students and service users both benefit from service user involvement in healthcare programmes
- There is limited evidence that service user involvement leads to changes in behaviour in practice or significantly benefits the service user receiving care
- Further consideration needs to be given to evaluation methodologies and strategies for involvement in recruitment, selection and assessment of students and activities in the practice setting
- A strategic, incremental approach to enhancing service user involvement is recommended
- Preparing service users for their role and students for service user involvement will enhance the success of the activities
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Table 1 Literature Search Terms *(preferred position page 7)*

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<tr>
<td>Physical therapy</td>
<td>Curriculum delivery</td>
<td>User</td>
<td>Patient-centred</td>
</tr>
<tr>
<td>Foundation degree</td>
<td>Curriculum assessment</td>
<td>Carer</td>
<td>Strategy</td>
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<tr>
<td>Healthcare practice foundation degree</td>
<td>Curriculum planning</td>
<td>Relative</td>
<td>Engagement</td>
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<td>Curriculum implementation</td>
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<tr>
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<td>Old people/ elderly/ aged</td>
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<td>Student recruitment</td>
<td>Young people/ children/ youth</td>
<td>development</td>
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<td>AHP</td>
<td>Course</td>
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<td>Course assessment</td>
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<td>Service User Involvement in Healthcare Education</td>
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<td>Speech and language therapy education</td>
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<td>Pharmacy training</td>
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<td>Allied health professions education</td>
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<td>AHP training</td>
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<td>Midwifery education</td>
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<td>Midwifery training</td>
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</table>
Service User Involvement in Healthcare Education

**Table 2** (preferred position page 9)

Modification of Kirkpatrick’s model for summative evaluation of educational interventions

<table>
<thead>
<tr>
<th>Level 1a</th>
<th>Learner perceptions</th>
<th>Students views on their learning experience (e.g. satisfaction, perceived impact on learning)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1b</td>
<td>Service user perceptions</td>
<td>Service users views on their involvement experience (e.g. motivation, costs and benefits)</td>
</tr>
<tr>
<td>Level 1c</td>
<td>Staff perceptions</td>
<td>Staff views on involving service users</td>
</tr>
<tr>
<td>Level 2</td>
<td>Modification of attitudes / acquisition of knowledge and skills</td>
<td>A measured change in attitudes, skills and knowledge (e.g. improvement in post-test scores, differences between comparison groups)</td>
</tr>
<tr>
<td>Level 3</td>
<td>Change in behaviour</td>
<td>Observation of whether the newly acquired skills, knowledge and attitudes are evident in the everyday practice of the student</td>
</tr>
<tr>
<td>Level 4</td>
<td>Benefits to service users</td>
<td>Assessment of whether there is a tangible difference to the health and well-being of service users who receive care from students exposed to user involvement</td>
</tr>
</tbody>
</table>
### Table 3 Curriculum Development (preferred position p 11)

<table>
<thead>
<tr>
<th>Study ID No</th>
<th>Authors</th>
<th>Programme / Professional Group</th>
<th>Model / Approach / Strategy</th>
<th>Strategy Evaluation</th>
<th>Findings</th>
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<tbody>
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<tr>
<td>1</td>
<td>Alahlafi &amp; Burge (2005)</td>
<td>UG medical education (psoriasis content)</td>
<td>Delphi study involving patients and professionals to help determine content</td>
<td>None</td>
<td>• Patients placed greater emphasis on psychosocial aspects of the condition, financial burden and complementary therapies than professionals did</td>
</tr>
</tbody>
</table>
| 2          | Calman (2006)            | Pre-registration nursing         | Study to ascertain patients’ perceptions of a competent nurse and to explore their willingness to be involved in assessment of students | None                | • Being friendly, kind, having human skills and going the extra mile were seen as added extras
• Most felt that the reality of assessing performance of nurses would be difficult, particularly if based on one incidence |
| 3          | Curle & Mitchell (2004)  | Doctorate in Clinical Psychology | Service user reference group set up to inform the curriculum | None                | • Led to enhanced user involvement and programme changes
• Qualities of a good and bad clinical psychologist generated |
| 4          | Forrest et al (2000)     | Pre-registration nursing (mental health) | Focus groups used to elicit mental health service users views about the attributes of a mental health nurse | None                | • Being able to function as a friendly human being was seen as key
• Emphasis should be placed on learning with service users |
<p>| 5          | Greenfield et al (2001)  | UG medical education            | Lay and professional representatives from 10 | None                | • Recommendations included recruiting more students from |</p>
<table>
<thead>
<tr>
<th></th>
<th>Study</th>
<th>Course/Programme</th>
<th>Research Methodology</th>
<th>Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Jordan et al (2000)</td>
<td>Pre-registration nursing (mental health)</td>
<td>Service users (and lecturers and students) were consulted in discussion groups</td>
<td>Students and lecturers placed minimal value on bioscience content. Service users identified that nurses lacked knowledge of pharmacology and would like the curriculum to include non-pharmacological interventions.</td>
<td>Established community groups representing a range of ethnic minorities were consulted in discussion groups. Students learning basic greetings in different languages and cultural awareness sessions being delivered by people from the Black community.</td>
</tr>
<tr>
<td>7</td>
<td>Flanagan (1999)</td>
<td>CPD cancer nursing course (Specialist practitioner qualification)</td>
<td>Involvement of carers and clients (with cancer) in the curriculum design group</td>
<td>Users and carers suggested that the educational process must promote not stifle the affective elements of care. Better preparation was advised as was the avoidance of jargon which promotes professional exclusivity.</td>
<td>None</td>
</tr>
<tr>
<td>8</td>
<td>Rudman (1996)</td>
<td>Pre-registration mental health nursing</td>
<td>Focus groups held with two service user groups to elicit views on curriculum and qualities of a mental health nurse</td>
<td>Users required professionals with an eclectic knowledge base tailored to individual needs and good interpersonal skills.</td>
<td>None</td>
</tr>
<tr>
<td>9</td>
<td>Sawley (2002)</td>
<td>Children’s nursing courses</td>
<td>A consumer group was set up to inform curriculum development</td>
<td>The reference group led to changes to educational content of programmes and practice development.</td>
<td>None</td>
</tr>
</tbody>
</table>
| 10 | Whittaker & Taylor (2004) | Module on parenting skills | Parents and professionals were asked their views on local parenting support services to inform a parenting module | None | • General dissonance was noted between practitioners and parents views  
• Sound interpersonal skills and inclusion of parents in decision making were seen as crucial by parents |

| Level 1 |

| 11 | Masters et al (2002) | Pre-registration Diploma in Nursing (Mental Health) | Strategy development group collected data to inform a service user involvement strategy for the curriculum | Survey of participants including users, carers and staff (n=17) | • Issues of representation and representativeness were a concern  
• Involvement led to personal development e.g. enhanced skills and confidence and changes in the curriculum philosophy |
### Table 4 Curriculum Delivery *(preferred position after page 11)*

<table>
<thead>
<tr>
<th>Study ID No</th>
<th>Authors</th>
<th>Programme / Professional Group</th>
<th>Model / Approach / Strategy</th>
<th>Strategy Evaluation (n=)</th>
<th>Key Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level 1</td>
<td></td>
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</tbody>
</table>
| 12          | Brown & Macintosh (2006) | CPD module on heart disease prevention in primary care (nursing focused) | Involvement module steering group and in e learning materials development including video stories | Qualitative study with patients (n=27) and students (n=10) | • Patients found process rewarding and enjoyable  
• Students reported that the videos heightened interest and motivation to learn  
• Assessors noted that the patient’s perspective was well evidenced in the module assignment |
| 13          | Butterworth & Livingston (1999) | UG medical education | Carers of dementia sufferers, as part of a formal lecturer programme, talked with medical students | Informal evaluation (numbers not stated) | • Students rated sessions highly  
• Carers felt that their caring had meaning and value and they wished to enhance the knowledge and practice of the doctors of tomorrow |
| 14          | Coleman & Murray (2002) | UG medical education (GP/ community attachment) | Medical students examine and question patients in their own home or surgery | Qualitative interviews with patients (n=15) | • Incentives for involvement were altruism and personal gain  
• Embarrassment and anxiety and concern about full access to records possibly prevented involvement |
<p>| 15          | Cooper &amp; Spencer- | UG medical, | Service users co- | Analysis of | • Students and facilitators found the |</p>
<table>
<thead>
<tr>
<th></th>
<th>Author (Year)</th>
<th>Healthcare Programmes</th>
<th>Method</th>
<th>Findings</th>
</tr>
</thead>
</table>
| 16 | Dawe (2006)   | Nursing, social work, OT, physiotherapy programmes | Facilitate interprofessional team working workshops, students’ reflection (n=63), a focus group with IPE facilitators (n=7) and in-depth interviews service users (n=10) | Experience rewarding  
- Students felt it enhanced their understanding of a patient-centred perspective  
- Service users felt well prepared and enjoyed contributing to better relationships between professional groups |
| 16 | Costello & Horne (2001) | Pre-registration nursing (adult branch) | Involvement of 3 patients in a classroom session facilitated by a lecturer, Basic end of session evaluation (n=67) and discussion with patients (n=3) | Students felt that it helped them gain an understanding of the patient’s perspective although some felt embarrassed  
- Patients found the process cathartic |
| 17 | Frisby (2001) | Pre-registration nursing (mental health) | Involvement of users in classroom based client review using student role plays, Informal feedback (numbers not stated) | Users reported enhanced feelings of empowerment  
- Very little resistance noted from tutors  
- Involvement promotes learning about users’ perspectives |
| 18 | Ikkos (2003 & 2005) | Psychiatry training for qualified doctors | Involvement of patients from user groups in a basic clinical interviewing skills workshop, Informal evaluation 34 doctors (n=34 in 2003 and 57 in 2006) | Sessions were rated highly and facilitated empathy and an appreciation of users role in decision making  
- The need for balanced expression of opinion and viewing the situation as a mutual learning opportunity was emphasised |
## Service User Involvement in Healthcare Education

<table>
<thead>
<tr>
<th></th>
<th>Authors</th>
<th>Description</th>
<th>Methodology</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td>Jackson et al (2003)</td>
<td>Accelerated UG medical education (Inequalities in Health Module)</td>
<td>Students interview patients who live in socially and economically deprived areas in their home and staff from 3 services involved in their care</td>
<td>Qualitative study with patients / carers (n=18) • Half of the patients were apprehensive and most were positive about being involved • All were willing to take part again • Being listened to was seen as a positive benefit • Involvement was seen as a way of improving the health service</td>
</tr>
<tr>
<td>20</td>
<td>Jones (2006)</td>
<td>Advanced practice clinical examination programme (nurses)</td>
<td>Service users acted as ‘patients’ in history taking and physical examination skills delivery</td>
<td>Qualitative interviews with service users (n=7) • Users found the process empowering and it increased their knowledge about their condition • They felt a sense of belonging and felt that their contributions were valued</td>
</tr>
<tr>
<td>21</td>
<td>Kelly &amp; Wykurz</td>
<td>UG Medical Education(1st and 2nd year)</td>
<td>Students made 5 visits to a patient partner and received formative feedback on communication and comments on summative work</td>
<td>Evaluation meetings involving 136 patient partners and 136 students. • Students reported enhanced communication skills • Patient partners reported increased confidence • The community tutors were positive</td>
</tr>
<tr>
<td>22</td>
<td>Khoo et al (2004)</td>
<td>Postgraduate Diploma / MA in mental health</td>
<td>Involvement of service users in classroom seminars</td>
<td>Survey of students (n=26) and qualitative interviews students (n=10) • Students rated the user contributions as good or excellent • Process fostered a desire to change services • Representativeness was questioned</td>
</tr>
</tbody>
</table>
## Service User Involvement in Healthcare Education

<table>
<thead>
<tr>
<th></th>
<th>Authors</th>
<th>Program</th>
<th>Description</th>
<th>Methodology</th>
<th>Findings</th>
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</table>
| 23| McAndrew & Samociuk (2003)           | Pre-registration nursing (mental health) | Service user involvement in classroom based reflection sessions             | Survey of students (n=7) and service users (n=5) at the start of the project | • Users felt that they were in the dominant position as they could offer real life experience  
• Students felt that through the process there would be sharing and growing for all concerned |
| 24| Maughan et al (2001)                 | UG medical education                    | Students meet a patient with cancer regularly over a 6 month period. Interactions are recorded in a diary and assessed | Informal evaluation (n=144)                                                | • Students reported increased confidence talking to patients with serious illnesses and gained insight into multi-disciplinary working and problems patients faced  
• Found it emotionally challenging when patient dies and problematic in relation to the assessment |
| 25| Ottewill et al (2006)                | Pre-registration physiotherapy          | Two patients who had experienced a stroke told their stories in the classroom | Qualitative interviews with students (n=6)                                 | • The impact on learning was considerable  
• The unconventionality of the session raised anxieties  
• Students assumed a more passive role than usual |
| 26| Read & Spall (2005)                  | Post-registration palliative care diploma (nurses) | Stories and biographies used to explore palliative care                      | Informal evaluation (n=6)                                                 | • Session gave an insight into users and carers feelings and enhanced their understanding of the meaning of illness |
| 27| Rush & Barker (2006)                 | Pre-registration Diploma in Nursing (Mental Health) | Involvement of service users in 3 EBL sessions                               | Survey of students (n=26)                                                  | • All students reported positive impact on their learning and service user involvement improved the EBL trigger |
## Service User Involvement in Healthcare Education

<table>
<thead>
<tr>
<th></th>
<th>Authors (Year)</th>
<th>Setting and Education</th>
<th>Methodology</th>
<th>Findings</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>28</td>
<td>Shah et al (2005)</td>
<td>UG pharmacy education (first year)</td>
<td>Patient volunteers lead a tutorial, were interviewed as part of history taking and communication skills development and gave formative feedback on performance</td>
<td>Qualitative interviews with patients (n=14)</td>
<td>Patients reported: - altruistic reasons for involvement - enhanced knowledge about their illnesses and medication - that they were more questioning of health care professionals - enhanced self-esteem and confidence and relief from social isolation</td>
</tr>
<tr>
<td>29</td>
<td>Simons et al (2006)</td>
<td>Mental health nursing programmes</td>
<td>Appointment of service user to an academic post</td>
<td>Anecdotal (full evaluation reported after cut off date)</td>
<td>The post facilitated user participation in education being part of everyday activities of the academic team and the post holder was able to support, appraise and review the contributions of other users</td>
</tr>
<tr>
<td>30</td>
<td>Stacy &amp; Spencer (1999)</td>
<td>UG Medical Education</td>
<td>Students visit a patient regularly over a 6 month period</td>
<td>Qualitative interviews with patients (n=20)</td>
<td>Patients saw themselves as experts in their own condition - They benefited from having someone to talk to and for some it relieved loneliness - It facilitated insight into their own condition - Some gained satisfaction from helping students in their education</td>
</tr>
<tr>
<td>31</td>
<td>Turner et al (2000)</td>
<td>Pre-registration programmes including medical, nursing, social work</td>
<td>Students interview carers of people with a terminal illness (or are)</td>
<td>Qualitative interviews with 12 carers (n=12) and focus groups with</td>
<td>Students felt privileged to hear the stories and behaved sensitively when carers became upset - Carers found it cathartic but would...</td>
</tr>
<tr>
<td>Level</td>
<td>Author(s) (Year)</td>
<td>Context</td>
<td>Methodology</td>
<td>Findings</td>
<td>Notes</td>
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<tr>
<td>32</td>
<td>Whitehead &amp; Harding (2006)</td>
<td>Post-registration module (gastrointestinal and liver)</td>
<td>Facilitation of a conference morning including service users and clinicians</td>
<td>Participant observation of session</td>
<td>None</td>
</tr>
<tr>
<td>33</td>
<td>Walters et al (2003)</td>
<td>UG medical education (year 4 psychiatry attachment)</td>
<td>Patients with mental disorders are interviewed by students in the GP surgery</td>
<td>Survey of patients (n=115) and qualitative interviews with patients (n=20), GP tutors (n=12) and students (n=14)</td>
<td>Personal benefits for patients included enhanced self-esteem, development of a coherent narrative and new insights into their health. The students were viewed as non-judgemental and enthusiastic. No distressing consequences were reported by students</td>
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<tr>
<td>34</td>
<td>Eagles et al (2001)</td>
<td>UG medical education (4th year psychiatry block)</td>
<td>Students were taught history taking skills by either a real patient (n=54), a simulated patient (n=46) or by observing a video tape of an interview (n=56)</td>
<td>Non-randomised comparison between the three groups. Outcomes measured included knowledge and attitudes</td>
<td>No significant differences found between the groups on knowledge and attitudes. There was a slightly higher satisfaction score for the simulated patient</td>
</tr>
<tr>
<td></td>
<td>Study</td>
<td>Level of Education</td>
<td>Description</td>
<td>Methods</td>
<td>Findings</td>
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| 35| Haq et al (2006)    | UG medical education (year 3) | Involvement of 4 Patient Partners (PP’s) with back pain in 2 clinically based teaching sessions | Non-randomised comparison (n=60 PP group and n=54 in control group) and qualitative focus groups with PP’s (n not given) | - PP’s took part for altruistic reasons and benefited from increased knowledge of their condition and increased confidence  
- There were no differences between OSCE scores between the two groups |
| 36| Raj et al (2006)    | UG medical education | Involvement of patient educators (PE) with arthritis to deliver the rheumatology curriculum | RCT with an experimental group (PE) (n=25) and a control group (n=25). Qualitative interviews with PE’s (n=6) and students (n=6). | - PE’s achieved acceptable scores on student evaluation of teaching form but doctor led teaching scored higher  
- No significant differences in OSCE scores between the two groups  
- PE’s enjoyed the training and reported an increase in self-worth and confidence and being able to use their illness in a positive way |
| 37| Wood & Wilson-Barnett (1999) | Pre-registration nursing (mental health branch) | Involvement of service users in classroom activities | Non randomised comparison (cross over) with 15 students in each group using a user centred measurement tool | - Service user input led to less use of professional jargon, more empathy and less distancing  
- Students exposed to input more likely to take an individualised approach to assessment and intervention  
- Students expressed concern about potential discomfort and representativeness |
| 38 | Klein (1999) | UG medical education (3\textsuperscript{rd} year) | Involvement of either patients with cancer (experimental group n=123) or patients with other diagnoses (control group n=126) in an interviewing skills training programme | RCT with measurement at the end of the sessions and at a 2 year follow up. An interview rating instrument was also used to rate a real life interview with a patient with cancer | • Students taught interviewing skills by patients with cancer demonstrated better communication skills than those taught by patients with other diagnoses |
### Table 5 Assessment of students (main focus) (preferred position after page 11)

<table>
<thead>
<tr>
<th>Study ID No</th>
<th>Authors</th>
<th>Programme / Professional Group</th>
<th>Model / Approach / Strategy</th>
<th>Strategy Evaluation (n=)</th>
<th>Findings</th>
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</thead>
<tbody>
<tr>
<td>Level 1</td>
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</table>
| 39          | Bailey (2005)   | MA Community Mental Health    | Users were asked their perceptions of summative work and gave feedback                      | Action research involving discussion with users and a focus group with programme participants (n=9) | • Users reported enhanced confidence and knowledge about services offered and new friendships                                                   
|             |                 |                               |                                                                                            |                                                                                           | • Students reported mixed views on the helpfulness of the feedback and generally wouldn’t make any major changes to their practice based on it |
### Table 6 Programme Evaluation (preferred position after page 11)

<table>
<thead>
<tr>
<th>Study ID No</th>
<th>Authors</th>
<th>Programme / Professional Group</th>
<th>Model / Approach / Strategy</th>
<th>Strategy Evaluation (n=)</th>
<th>Findings</th>
</tr>
</thead>
</table>
| 40          | Forrest et al (2004) Part I (methodology) and II (outcomes) | CPD course on Psycho-social interventions (PSI) | Stakeholder conference and meetings with users and carers to generate programme evaluation outcomes | Involvement of service users in evaluation not evaluated | - Development of a good working relationship was seen as important  
- Only one service user was aware of what PSI was and none were aware of receiving it. The qualities of the worker were seen as more important than the intervention |
### Table 7 Integrated Strategy (preferred position after page 11)

<table>
<thead>
<tr>
<th>Study ID No</th>
<th>Authors</th>
<th>Programme / Professional Group</th>
<th>Model / Approach / Strategy</th>
<th>Strategy Evaluation (n=)</th>
<th>Findings</th>
</tr>
</thead>
</table>
| Level 4b    | Barnes et al 2000 & 2006 | MA Community Mental Health | Service user involvement in programme commissioning, selection of staff, programme board and curriculum committee, programme delivery and evaluation | Formal external evaluation using a variety of methods to look at changes in knowledge, attitudes, skills and user generated practice outcomes | - Programme participants agreed with the user centred values of the programme.  
- Some user contributions were perceived as too antagonistic by participants  
- All could describe how their practice had developed to enhance user involvement  
- A higher proportion of programme participants’ users reported good user-centred assessment and care planning compared to a comparison group |