

User and carer involvement in the training and education of health professionals: A review of the literature

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Abstract

Background: Health policy requires consumer involvement in services, research and education but little is known about how consumers are being involved in healthcare education, the effect on learning and practice, nor how involvement initiatives are being evaluated.

Objectives: To describe methods of involving consumers in healthcare education, discuss ways in which initiatives have been evaluated, and identify areas for development in education, practice and research.

Design: All papers reporting specific initiatives involving consumers in health care worker training and education were included. Viewpoint articles and studies of consumers training consumers were excluded.

Data sources: Cinahl, Medline, Assia, PsycINFO, British Nursing Index, Social Science Citation Index, citations from reference lists, relevant websites and personal communication with key people known to be working in this area.

Review methods: A narrative approach was taken with categorisation of data to reflect objectives of selected studies; method of involvement; process issues and evaluation.

Results: Thirty-eight papers were included; most provide small-scale qualitative studies of mental health service users and focus on process rather than outcome. Various methods of involvement are described and consumers consistently prioritise the need for training in interpersonal skills over 'technical' skills. There is little research into organisational strategies and no studies investigate the effect of consumer involvement on practice. Two studies indicated that students exposed to consumer involvement demonstrate more empathic understanding and better communication skills.

Conclusions: There is tentative evidence that consumer involvement in training enhances workers' skills in the manner prioritised by consumers. However, if consumer involvement in training and education is to facilitate services that reflect the priorities of the people using them, it must be developed in partnership with service providers; further research is needed to explore the impact of consumer involvement and to track the development of organisational consumer involvement strategies, also systems for supporting consumers need to be established, including training for both consumers and staff.

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Keywords: Consumer involvement; Education and training

What is already known about the topic?

- As health services increasingly focus on patients' choices, consumer involvement in training and education has been recommended by professional bodies.

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- Guidelines for consumer involvement in training and education have been developed.
- Small-scale studies of consumer involvement have been published, but these have limited external validity.

What this paper adds

Bringing together the findings of all published studies illustrates

- different methods of consumer involvement,
- the areas of healthcare in which they have been tried,
- their impact on consumers and students,
- gaps in knowledge, and
- areas for future development.

1. Background

The importance of involving consumers in all aspects of health care began to permeate UK government policy in the 1980s and was firmly enshrined by the 1990s. The Community Care Act (1990) clearly placed consumer involvement upon the health care agenda with 'choice and independence' as its underlying principles. Subsequent health policy and legislation have confirmed this principle as an essential part of the modernisation agenda. This has resulted in the development of structures for consumer involvement within services (DoH, 1999), in research (DoH, 1998) and in education (for example, 'Tomorrow's Doctors' (GMC, 1993); 'Changing the Culture: Involving service users in social work education' (Beresford, 1994); and 'Learning From Each Other' (ENB, 1996)).

The first response to these requirements for healthcare education came from the field of mental health: educational institutions and workforce confederations have been developing guidelines and audit tools for involving mental health service users and carers in education and training (Northern Centre for Mental Health, 2003; Tew et al., 2004). At a more generic and systemic level, a number of Universities (e.g. Dundee, Brighton and Central Lancashire) are developing School-Wide strategies for consumer involvement in all aspects of course staffing, planning, development, delivery and evaluation. However, little is known about how (or how much) it is being implemented, how successful different involvement approaches are, nor how this success is being evaluated. The aim of this review is therefore, to identify both published and grey literature on the involvement of service users and carers in the planning, delivery and evaluation of training and education for health professionals in order to: describe approaches taken to involve consumers in the education

of health professionals and the advantages, disadvantages, impact and ethical implications of different approaches; discuss the methods used to evaluate involvement; and, consider the gaps remaining in both practice and research into consumer involvement.

2. Method

2.1. Search strategy

A variety of search methods were employed to ensure all the relevant literature was identified. The databases searched were: Cinahl, Medline, Assia, PsycINFO, British Nursing Index, Social Science Citation Index with no date or location restrictions. Citations were followed up from reference lists of retrieved articles. Relevant websites were consulted and personal communication with key people known to be working in this area aimed to reveal any ongoing work. A combination of thesaurus and free text search terms were used including nursing/medical, education/teaching/learning, consumers/users/patients/lay/public/carers, involvement/collaboration/participation. Over 2000 citations were identified. Of these, *all* papers in English language describing a study or project in which consumers were involved in education and training of health care professionals were retrieved. These were read and sorted by both authors, excluding only those papers about consumer involvement in the education of other patients (e.g. through expert patient/peer education initiatives), or viewpoint/opinion papers. Thirty-eight papers met the inclusion criteria.

It is worth commenting on this inclusive approach. A number of authors have advocated applying the principles of traditional (quantitative) systematic reviews to qualitative research (Blaxter, 1996; Popay et al., 1998) with appraisal of each piece of literature (see Popay et al., 1998; Mays and Pope, 2000). However, there is no accepted hierarchy of process or evidence in qualitative research; adherence to a given checklist runs the risk of underestimating the usefulness of evidence that can be yielded from literature of a less rigorous methodological quality (Mays and Pope, 2002); and in certain professional journals details of research methods are often inadequate to make a judgement about the quality of the study (Popay et al., 1998). This is even more pertinent in a review of consumer involvement since reports and papers written by consumers are less likely to achieve publication.

2.2. Analysis

A systematic approach was taken to organise the data according to the research objectives. First the overarching subject covered in all papers was identified: all described a particular involvement *method*. Second, common issues

related to the *process* of consumer involvement were identified across all the papers (such as ethical concerns, implications for training consumer-trainers). Third, ways of *evaluating* consumer involvement were described. Through synthesis of data falling into these three overarching categories, systematic themes were identified linking the underpinning philosophy of initiatives with conceptions of outcome, and staff attitudes with the need for staff training and consumer support; these are considered in the discussion.

3. Findings

3.1. *Methods of consumer involvement*

3.1.1. *Gaining consumers' views and experiences*

One way of including the users' perspective in education is by means of advisory groups; these may constitute existing groups, reference or focus groups set up for the purpose, or conferences with invited representatives from a range of interest groups. Harrison and Beresford (1994) describe the use of a conference as a means of consulting a range of different consumer groups in order to inform social work training for CCETSW. Key points to emerge from this exercise included the need for supported consumer involvement throughout training, the potential for consumer involvement to increase the knowledge base for training and the need for diversity in those involved.

Two papers discuss the process of forming reference groups from existing consumer groups (Ingham, 2001; Sawley, 2002). Ingham (2001) set up a reference group to provide a user perspective on a new pre-registration nursing course. Like the CCETSW conference, this group addressed the process of involvement, but the recommendations reflect greater concern with maintaining control over the process and content—perhaps in line with a more traditional medical approach. For example: the patient must have come to terms with his/her disability, condition, treatment and related matters; the patient should share his/her experience without becoming angry; patient contributions need to be guided, and student questions may also need to be guided to protect the user from 'no go' topics.

At a more specific level, Flanagan (1999) reports on the process of involving clients and carers of children with cancer in curriculum development. They were invited to join meetings over a period of months and this was perceived to lead to a curriculum that was "grounded in the reality of human experience"; prospective students had the opportunity to learn from the perspective of people they are caring for; and the meetings enabled current professional issues to be debated with those who had received nursing care.

Rather than focussing on the *process* of involvement, Sawley (2002) describes a series of meetings set up with consumers to specifically inform the curriculum *content* of children's nursing courses. Recruitment for the group was made through a variety of routes including advertisements and invitations. There were clear guidelines for the meeting to ensure that attendees focused upon issues they found important rather than any unresolved conflicts or disputes with respect to specific incidents. Changes were made to the educational content of the courses as a direct result of these meetings the initiative also led to practice development within the Trusts and more effective networking.

Greenfield et al. (2001) approached 12 established community groups to nominate representatives for focus groups to discuss how future doctors could best serve diverse communities. Responses fell into three broad themes: the cultural beliefs and behaviours of their community; the characteristics of a culturally sensitive doctor; and, recommendations for medical education. Changes were made to the curriculum content as a direct result of this study and these were fed back to the community groups.

Three further studies report 'surveys' of mental health service users' views on the training needs of mental health nurses. In these reports, the emphasis was placed on findings rather than process and all reported service users' emphasis upon interpersonal skills and the humanistic qualities of caring and respect compared with practitioners' objectives to provide therapeutic and professional interventions (Mansfield et al., 1982; Rudman, 1996; Forrest et al., 2000).

3.1.2. *Producing learning materials*

All three papers describing service users' involvement in producing learning materials were from the field of mental health. Coupland et al. (2001) describe the process of making a video with service users to demonstrate using a specific psychiatric assessment tool. Whereas professional guidance for this tool focussed on psychological factors, the user led video provided the opportunity to include the sociological and personal aspects of a person's mental health problem. Ah-man (1999) also describes making a video as part of a training package for use in the training of mental health workers. 'Learning from Psychosis' draws on the experience of the authors and includes experiential exercises and evocative artwork. The service users in both of these studies are reported to have found the experience positive.

However, the experience of the service user in the third paper (Reynolds and Read, 1999) was more complex and ambiguous. When consumers were invited to collaborate in the development of learning materials for Open University students there were conflicting views about juxtaposing user accounts alongside

professional accounts within the same publication. Reynolds (a service user) believed that this would lead to the discrediting of the users' accounts due to the imbalance in credibility and power afforded service users. However, the course team (who continued to meet without service user representation) decided to press ahead with this idea in order to 'maintain balance'. This raises questions about the status of service users' views. The perception that these need to be balanced, clarified or corrected by professionals needs open and full debate.

3.1.3. Consumers as teaching aids

Patients have long been involved in the teaching of medical students. Traditionally this has been a passive role involving bedside teaching rounds and examination of patients with known conditions with subsequent assessment of clinical knowledge and skills (Medio and Morewitz, 1992; Wykurtz and Kelly, 2002; Stacy and Spencer, 1999). Although there appears to be no research into the effect of this type of involvement on students' skills or attitudes, studies conducted over the past 30 years suggest a positive response from patients on their involvement in the teaching of medical students (Arnold, 1992; Mayo-Smith et al., 1992).

Three papers focus upon patient participation in community teaching through a system in which patients are partnered with General Practice medical students with the specific remit of teaching them about their symptoms (Dinsdale, 1999; Stacy and Spencer, 1999; Coleman and Murray, 2002). Stacy and Spencer (1999) interviewed 20 'patient partners' about their perceptions of this programme. They felt they learnt more about their condition and about the training of doctors, and they felt useful in helping students learn. The authors noted that a minority of patients felt that they may have been exploited when students were perceived as patronising or refused to disclose their written notes. In a similar study of 15 patients participating in community teaching programmes, (Coleman and Murray, 2002) all felt extremely positive about participation in the project. The two main motivations for taking part were altruism and personal gain. However, some expressed anxiety about intimate examinations, and some patients were not clear that their consent to see students also covered consent for students to have access to medical notes. However, Twinn (1995) reports divergent views among 24 female clients in a case study of health visitor training. The author suggests that this reflects the wide range of experience and expertise of health visitor students and the different levels of confidence and expertise of clients.

In a review of the literature on patients' involvement in medical education, Spencer et al. (2000) suggest the use of a framework to stimulate more careful consideration about the involvement of patients in medical education using the headings *Who? How? What? Where?* Whilst this framework provides a useful starting point, the findings of

the studies above indicate other issues that need to be considered including: gaining informed consent so that participants are clear about their role and their rights; systems of support for involved consumers need to be developed, with ongoing access to project organisers to clarify concerns and express reservations.

Consent. Two papers focused upon the issue of patient consent to medical student involvement in examination and treatment. Grant (1994) found that patients were strongly in favour of taking part in clinical teaching, except for those attending the sexually transmitted diseases clinic. Ubel and Silver-Isenstadt's (2000) found that decisions about consent to involvement with students were influenced by the type of procedure rather than the nature of the problem. These papers do not discuss the ethical dilemmas inherent in asking patients to allow students to observe or undertake a health care procedure. Yet it is likely that some people will find it difficult to refuse student involvement in their care for fear of being considered unreasonable, or jeopardising their own treatment and care in some way.

3.1.4. Consumer involvement in the classroom

Established groups. Rowley (1995) describes a deliberate strategy to integrate a service user perspective in their social work training programme by recruiting service users as course members. This was reviewed following five courses, including a total of 12 service users. Overall service users and professionals reported that it was useful in breaking down barriers, users felt that they were treated equally and practitioners felt more able to see the field of mental health from the users' perspective. However difficulties remunerating service user trainees reduced their access the course.

Carers (Evans, 1994) and service users (Soliman and Butterworth, 1998) have themselves taken the initiative to get involved in the training of professionals in a bid to increase awareness of user and carer experiences and perspectives. Both groups report positive results as they have become increasingly involved in a range of different educational initiatives; they feel their contribution is valued and it has further empowered them to act as agents of change.

Personal stories. Anecdotally, the most common consumer involvement practice in health care education is to invite an individual to tell their own story, yet there are few published accounts and no evaluations of this approach. Hutchings (1999) describes the experience of involving one patient (*K*) to present his perspective and experience to his unit's nursing staff. The author reports that nurses began to see *K* as an expert shifting the power base closer to that of equal partnership. Chapman (1996) describes mental health service users teaching student nurses in a more unusual environment. Consumers and students came together for 'an evening of dinner and conversation'. Following their introduction, the consumers were asked to

'pick a student and tell them about your experiences and coping strategies around a period of crisis'. Four users' stories' are offered as example, however, there is no discussion as to the benefits or drawbacks of this event from either the consumers' or the students' perspectives.

Service users assessing students. Service users describe the experience of assessing social work students on their learning disability placement as rewarding and beneficial (Cole, 1994). Mental health service users involved in client review presentations as part of the formative assessment of nursing students (Frisby, 2001) reported a feeling of empowerment, students felt it gave them a deeper understanding of how their interventions effect clients but, they also found that some users' views reflected a non-accountable position, which if carried through, might incur unethical practice. The author argues that professional accountability during the sessions remains with the lecturer and that it is sometimes necessary to challenge ideas in a supportive and constructive way. Failing to do so, he asserts, is to promote tokenistic compliance.

Barriers to involvement. Felton and Stickley (2004) interviewed five mental health lecturers to ascertain their views of involving service users in teaching the undergraduate mental health nursing programme. Respondents were not clear about the advantages of user involvement in education. They were, however, concerned that someone who was mentally ill would not be able to teach large groups of students and if they were, then they could not be considered representative of the core group of users, thus indicating a kind of 'catch 22' situation. Another perceived disadvantage for the users becoming professionalized was an erosion of their own roles into that of 'glorified markers'. The study confirms the need for ongoing development of teachers through training, clinical practice and exposure to contemporary debate.

3.2. Evaluations of consumer involvement

Two papers reported case study evaluations of University based projects. Barnes et al. (2000) report a case study of a post-graduate programme in community mental health. Methods of data collection included documentary analysis, and interviews with key participants including user representatives; a survey of user groups. Educational providers were able to demonstrate that service users were involved in all aspects of course development and implementation. Although users' contributions were valued, but roles and responsibilities were constrained by the formal university requirements and they were not given the same credence by the programme participants as senior academics from the field of psychiatry and psychology.

Barnes et al. (2000) also describe the development of a questionnaire to assess 'added value' for service users which could be attributed to the programme. Service

users developed (and verified with other user groups) outcome indicators for the course which concur with training needs identified earlier in this review: students should demonstrate understanding and not just try to solve problems or push people into services, they should treat service users with respect not as labels and have knowledge about services (including advocacy services and service user groups), and should involve service users in assessing their own needs.

In a case study of service users in mental health training (Masters et al., 2002; Forrest et al., 2000). project members perceived a change in power, status and working relationships derived from working within a group of 'like minded' people. The service users found benefits in learning new skills, increased self-confidence and a genuine feeling of empowerment. However, university lecturers who were not involved in the project felt 'left out' and called for a wider ownership of the project. A further area of concern related the 'ideal' of user involvement taught on the course and the 'grim reality of practice'.

Both of these studies were concerned with education in mental health. Both reported that service users value most highly the humanistic skills of students; both led to increased 'power sharing', but in both studies this was limited within the University environment. Both studies also highlighted that keeping the momentum going for user involvement in professional education requires high levels of energy and commitment.

3.2.1. Evaluation of teaching in the classroom

Three papers evaluated users and carers teaching in the classroom. Their methods differed, but reported findings were similar. Turner et al. (2000) evaluated carer involvement in interprofessional workshops in palliative care. A specialist evaluator attended three workshops as a non-participant observer, taking field notes. At the end of each workshop students were invited to participate in a semi-structured interview and at the end of the term all carers who had been involved in the workshops were invited to a feedback meeting. Twelve out of a possible 28 carers attended and one carer sent written feedback.

Costello and Horne (2001) evaluated patient involvement in the teaching of a general pre-registration nursing programme. Three patients were involved on the basis of their willingness to take part. Each teaching session lasted 50 minutes and took place within a period of 6 weeks. Twenty-three students attended each of the three teaching sessions. At the end of each session the students were asked to complete a questionnaire about different aspects of the session and user involvement in nurse education generally. Sixty-seven out of a possible 69 questionnaires were returned. The lead author discussed the session with each patient. Data was analysed using quasi-statistical content analysis based on identifying the frequency of responses to each item in the questionnaire.

Curran (1997) reviewed mental health workshops in which service users were involved. Taking a participatory approach, individual interviews were conducted with all participants (students and facilitators) and after initial data analysis, a further workshop was run to consider the implication of findings for social work education.

All three studies found that both students and user/carer participants found the experience positive. The students felt that listening to the user and carer perspective had facilitated a greater understanding, they found the experience moving, informative and instructive (Turner et al., 2000). Students valued the opportunity to hear users' views and to develop self-awareness for critical reflective practice (Curran, 1997). Other students were grateful to be able to benefit from listening to real experiences instead of hypothetical cases (Costello and Horne, 2001). Although some of the students in Costello and Horne's study also found that the patients' presence made them feel embarrassed and somewhat inhibited, Turner et al. (2000) reported that the students coped well when a carer became distressed. The users and carers in the studies found the experience cathartic, a chance to put their '2 penneth in' (Costello and Horne, 2001) as they do not have many opportunities to unload on the busy wards (Turner et al., 2000). The motivation for involvement was a desire to improve services, to give students the experience of human feelings (Turner et al., 2000) and to break down stereotypes of passivity and dependence (Curran, 1997).

3.2.2. *Evaluation of the effect of consumer involvement on student learning*

Although no studies evaluated the effect of consumer involvement on practice, two studies evaluated the effect of user involvement on student learning. In Wood and Wilson-Barnett's (1999) study, members of a local user group were involved in classroom teaching on the mental health branch of the pre-registration Diploma in nursing programme. A comparison design was adopted to measure the effects of the differing exposure to user involvement between two groups of students within the same cohort. Group 1 received user participation sessions in term six, group 2 received user participation in term seven. On completion of terms six and seven the students' approach to mental health assessment was tested by means of a video showing a simulated assessment followed by a short questionnaire. Replies were measured using a specifically designed tool providing user-centred criteria including the avoidance of medical and professional jargon; demonstration of empathic understanding (based on accurate and sensitive understanding of the person's story); and, an individualised (rather than standardised) approach.

Klein (1999) evaluated the effects upon third year medical students of involving cancer patients in the

teaching of communication skills. A prospective randomised controlled study was carried out involving two cohorts of third year medical students. The experimental group comprised 123 students who were taught with cancer patients and the control group comprised 126 students who were taught with patients with other diagnoses. Students were assessed through a brief video recording of an interview with a real patient and questionnaires measuring attitudes and behaviour.

The findings from both studies showed marked differences between students who were and were not exposed to service users with students in the exposed groups showing more concern about the impact of illness and symptoms upon the patients' lives. The nursing students from group 1 were found to use less professional jargon and were more likely to use lay terminology (Wood and Wilson-Barnett, 1999). Likewise the medical students in the experimental group felt that the ability to listen to the patient and build up trust was the essential components of the doctor-patient relationship (Klein, 1999). The medical students exposed to cancer patients also believed that clinical decisions should reflect the patient's wishes even if this went against the normal medical approach or philosophy; for example, by not telling someone their illness was terminal if they had expressed a wish not to be told (Klein, 1999). The nurses in group 1 were also able to demonstrate a tendency towards an individualised approach and this remained higher even at the end of term 7, leading the authors to conclude that involving service users earlier rather than later in a programme may be more effective in terms of influencing learning (Wood and Wilson-Barnett, 1999). The medical students in the experimental group also maintained the difference in attitude at the two year follow up study, in particular their view that the ability of doctors to communicate with patients is of great importance (Klein, 1999).

Although these studies are small and each has methodological flaws, they provide encouraging evidence that service user involvement in education may have an effect on students' interpersonal skills and empathic understanding. It is just such skills that service users have been shown to prioritise throughout the different types of studies reported in this review.

3.2.3. *Preparation of consumers*

Few of the papers specified whether, or how, user or carer participants had been prepared for their educational role, nor how support was organised. Where preparation was reported, it tended to be informal such as a short telephone call (Turner et al., 2000) or a briefing before a teaching session to explain the role of the participant (Costello and Horne, 2001). However, two studies had the preparation of service users for involvement in education as the main focus, one preparing patient instructors for teaching in rheumatology care (Gall et al., 1984) and one

preparing mental health service users to teach in the pre-registration mental health nursing branch (Hanson and Mitchell, 2001). Gall et al. (1984) recruited eight patient instructors (PI) who met stringent criteria (e.g. relatively stable, advanced rheumatic disease; above-average intelligence and verbal ability; adequate mobility for independent transfer from an examining table...) for thirty hours of individualised teaching, using a variety of aids, and covering medical terminology, the anatomy of the musculo-skeletal system, and techniques of the physical examination. By contrast, the only criteria necessary to join the mental health trainers programme was motivation to use their experiences to help others gain a greater understanding of mental health issues (Hanson and Mitchell, 2001). This course was more concerned with the techniques for the teaching itself and was based on a teaching and assessing module for nurses (ENB 998). Both courses provided support for the patient/user learners for the duration of the course.

The participants evaluated both courses positively. The mental health service users had become involved in various involvement activities and all agreed that the course had given them the skills and confidence to become involved. The Patient Instructors all stated that the project was worthwhile and enjoyable and wanted to continue with the scheme (Gall et al., 1984). These two preparation courses clearly had different goals. Mental health service users were prepared in the skills necessary to convey their own views and experiences in teaching sessions; whilst the emphasis of the Patient Instructors' training focused on what to teach rather than how to teach it. This begs questions about the purpose of user involvement: is it intended to convey medical knowledge about disease and its treatment, or to improve practice and services by raising awareness of consumers' views, experiences and priorities?

4. Discussion

Out of the 38 papers selected only two papers reported *carer* involvement in education and training, the remaining focussed on the involvement of service users, and over half of the selected papers reported on the involvement of *mental health* service users demonstrating the relative interest in this area of health care. The approaches to consumer involvement in education and training included: gaining consumers' views through surveys, reference groups, conferences and invitation onto existing groups; consumer involvement in the production of learning materials and consumers as teachers and assessors. Only seven papers evaluated the outcome of user involvement in terms of students' learning and there appeared to be no study assessing the effects upon health care *practice*.

The response to user and carer involvement in education and training is mainly positive. Consumers'

motivation for getting involved is generally a desire to improve services and a wish to 'give something back'. They describe the benefits from the experience as catharsis, further knowledge, an increase in confidence and self worth and a feeling of empowerment. Students report that hearing real life experiences from consumer educators enhances their understanding. This may seem surprising when this opportunity exists in their routine practice. The difference appears to lie in the roles played by students and consumers. Perhaps further user involvement in training will erode students' expectations that they must assume the role of 'experts' when in practice; once they are able to conceive of service users and carers as experts in their own experiences they may be able to learn as much from the accounts they hear in practice as those provided in the classroom.

Where consumers are involved in the planning of curricula they can influence content, teaching methods and teaching personnel to ensure that their priorities are reflected. In all studies that included user or carer views on what should be taught or what skills a health professional should have, the emphasis was consistently on the humanistic and interpersonal components of caring rather than the professional and technical. It must however be noted, that the studies reporting users' views all focussed on mental health service users views—and these may differ from the views of people using other health services. Whilst only two studies measured the effects of user involvement on learning, both findings indicated that the biggest difference between students exposed and not exposed to user involvement was their ability to demonstrate empathic understanding, an individual approach and an appreciation of good communication skills. This suggests that one way of producing practitioners with skills and qualities the service users and carers want is by involving service users and carers in their training.

Although consumer involvement was generally received positively, a number of studies revealed concerns from the perspective of both consumers and teachers. The two most common concerns for consumers were remuneration and preparation. Only five papers described how the user/carer trainers had been remunerated and/or prepared for their role. Organisations clearly need to develop systems of training (for staff and consumers), support and payment (these issues are comprehensively addressed in guidelines for the involvement of consumers in education, Tew et al., 2004). In addition, some service users found privacy, embarrassment and professional jargon provided difficulties for involvement, and one study reported misunderstandings in the implications of patient consent. Full information about the implications of involvement, the role of the involved consumer and their rights is needed before consent is sought.

User and carer involvement in health care education is based on an assumption that it will improve services and reduce the power imbalance between providers and

consumers. However, imbalances of power and control in favour of the professional or organisation were evident throughout reported studies. Examples include: more credence being given, by students, to teacher led sessions; adherence to the rules, regulations, or traditions of the academic institution regardless of the implications for consumers; a desire to ensure 'academic balance' to consumers' accounts; a wish to promote the professional accountability of the lecturer. Not all teachers/academics viewed involvement positively. Some were unconvinced about the benefits of consumer involvement, and worried that it might threaten their own role as educators. Some expressed concerns about ethical aspects such as accountability (i.e. the users may advocate something that would compromise professional accountability) or placing consumers in a position in which they had to revisit a painful experience. However, consumers themselves did not express the same concerns; their accounts suggested that recounting experiences could be helpful. Such issues need debate with equal representation from consumers and academics/professionals before a true partnership model is to be realised and implemented by the professional training institutions.

User and carer involvement clearly requires a great deal of ongoing commitment and motivation. This can prove too much for individual instigators, yet involvement initiatives were most frequently focussed on a single course rather than organisational strategies. School-wide strategies are being developed in a number of universities, but as yet there is no research into the development or impact of such wide-spread or long-term approaches. If the patronising culture that reportedly endures in educational institutions is to be challenged, then consumer involvement needs to be approached at the systems level; operating at all levels and in all aspects of the organisation including the selection of students and staff, the development of portfolios of courses, the planning of curricula and the delivery and assessment of teaching.

Finally, since the aim of training and education is ultimately to improve health care, educational institutions need to work in tandem with service providers towards the joint goal of providing services that value the expertise of those using them and meet their expectations, wishes and priorities.

5. Recommendations

If consumer involvement in training and education is to facilitate services that reflect the wishes and priorities of the people using them, then it must be developed in partnership, across education and service delivery.

Further research is needed to explore the impact of both service user and carer involvement in education and training on students' attitudes, behaviour and practice, and to compare different ways of involving consumers.

Organisational involvement strategies need to be developed and tracked to identify process issues (such as the potential barriers and ways of overcoming these), and outcome (for example impact on staff and student selection, staff and student attitudes, portfolio of courses, course content and teaching methods).

Staff and consumers need training in the purpose of consumer involvement and in ways of providing support for involved consumers. Systems for immediate and accessible payment should be set up, and evaluation (of consumers, teachers and students' experiences) should be a part of every initiative.

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