

**A Review of the Literature on User and Carer Involvement in the  
Training and Education of Health Professionals**

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**September 2004**

## **ACKNOWLEDGEMENTS**

We would like to thank The Sheffield Health and Social Care Research Consortium  
for funding this project.

## EXECUTIVE SUMMARY

### Background

The rapid development of service user and carer involvement in health services is a reflection of our increasingly consumerist society yet it places particular challenges in the healthcare arena which is built upon hierarchies of power based on implicit trust in medical expertise. In this context, valuing the views and experiences of people who use those services requires radical change so that health workers recognise the expertise of experience and work towards providing the types of interventions perceived to be most effective by those receiving the service in the manner that is most acceptable to them. Consumer<sup>1</sup> led pressure groups have accelerated policy developments and there is now a general expectation that consumers will be involved in research, education, service commissioning and delivery. Guidelines have been developed to inform ethical (safe, effective, non-exploitative) practice in the involvement of users and carers in research, education and practice. Reviews of consumer involvement in research have also been published however, there has been no rigorous review of consumer involvement in the education and training of health care professionals.

### Aim of review

The aim of this review is therefore to explore the literature on consumer involvement in the education and training of health care workers in order to

- a) describe existing models/approaches, their advantages, disadvantages and impact;
- b) discuss ways in which these initiatives have been evaluated, and
- c) identify areas for further work in both practice and research into consumer involvement.

### Method

A variety of search methods were employed to ensure all the relevant literature was identified. The major health and social science databases were searched; citations were followed up from reference lists and bibliographies from retrieved articles; relevant websites were consulted and personal communication was made with key people known to be working in this area. A combination of thesaurus and free text search terms were used to capture papers using a range of terms for consumer involvement, and for education, teaching and training courses. No date, language or study type restrictions were applied at the search stage.

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<sup>1</sup> Various terms are used as shorthand for the people who use/receive health services and those who provide informal care (e.g. public, lay, patient, service users, carers), each carries different connotations. For the purpose

Selection criteria were broad. All papers describing a study or project in which consumers were involved in education and training of health care professionals were included. At the point of selection, no judgement was made about the quality of the initiative/research. Papers were excluded if they referred to consumer involvement in the education of other patients (e.g. through expert patient/peer education initiatives), or provided a commentary or opinion on user involvement in general rather than focussing on a specific initiative/project. Over two thousand references were identified, 216 papers were retrieved and 38 papers were included in the review.

## **Findings**

The majority of papers provided descriptions of consumer involvement projects or more formal reports on small scale qualitative research. The emphasis was generally about the process of user involvement (how and whether it could be achieved) rather than upon its effect. Indeed the purpose of many of the projects described was ‘to involve service users’ rather than to improve practice in any specified way. Only 7 papers reported the outcome of consumer involvement in training/education and none examined the effect of such education on practice. Most papers described service user involvement however two projects involving carers were described.

A number of different approaches to the involvement of consumer were described including: consultation with consumers about content of training; creating a consumer reference group to advise on curricula; surveying the views of consumers about what should be taught; consumers producing learning materials; and, consumers as teachers and assessors.

Overall, consumer involvement was described as a positive process, well received by the service users and carers involved, students and teachers. Consumers chose to become involved in an effort to improve services or through a wish to ‘give something back’. They reported some personal benefits as a result of their involvement (catharsis, increased knowledge, an increase in confidence, self esteem and confidence), but in some cases reservations about the process were expressed, particularly concerning preparation and remuneration. Students clearly appreciated the opportunity to hear the first hand experiences of service users and carers in the classroom. They felt this gave them further insight into the experience of mental health problems and experiences of receiving mental health services.

Although the process of consumer involvement was generally initiated by teaching staff, some had reservations about the process. Concerns were expressed about ethical issues, their own professional

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of this review the term consumer is used because it covers both service users and carers. In reporting specific studies, the authors’ own language is used to describe the consumer group involved.

accountability for what was taught, and the risks incurred when service users were recounting painful experiences.

In all studies exploring consumers' views about what should be taught or what skills health professionals should learn, there was an emphasis on the humanistic and interpersonal aspects of caring rather than upon 'technical' or 'professional' skills. Only two studies measured the effects of user involvement on learning and both indicated that the main difference in students exposed to consumer involvement was their ability to demonstrate empathic understanding, an individual approach and good communication skills. This suggests that one way of producing practitioners with the skills and qualities that service users and carers want is by involving service users and carers in their training.

## **Discussion**

Recent developments in consumer involvement in education and training appear to be based upon the assumption that this will lead to practice that is more closely aligned with consumers' wishes and expectations. However there is very little evidence that consumer involvement changes practice, indeed most involvement reports on consumer involvement focus more on the process (how and whether involvement can be achieved) than on outcome. This review demonstrates that there are a number of different ways of involving consumers in education and training all of which are largely positively received by the consumers involved, students and teachers. Although two studies have found that students exposed to user involvement in their training report improved communication skills and understanding of service users experiences, no studies have investigated the impact of such training on practice. The research that has been undertaken in this area takes the form of small, mainly qualitative, convenience studies with no systematic or rigorous evaluations of best-practice initiatives.

Although consumers generally find the process of involvement rewarding, it is clearly important that appropriate systems of preparation, support and remuneration are developed (for extensive advice on such processes see Tew et al, 2004). 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. Where consumers provide teaching in the classroom it is received positively by students, but this begs questions about how students respond to patients' accounts in practice placements and the influence of expected role upon their responses. Perhaps further user involvement in training will gradually erode students' expectations that they must be seen as the 'experts' 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.

Most of the involvement initiatives reported are specific to a particular course or module, there is little research into the development or impact of system level organisational consumer involvement strategies. It is apparent, from the one study into teachers' attitudes to consumer involvement, that a patronising culture endures within educational establishments. Teachers are concerned about the effect of consumer involvement in training and education upon their own professional standing and upon consumers' mental health. If this is to be challenged, consumer involvement needs to be approached at the systems level, operating at all levels of the educational institution, and in all aspects of the organisation from the selection of students and staff, the development of portfolios of courses, the planning of curricula and the delivery and assessment of teaching.

### **Recommendations**

- Consumer involvement should be developed in partnership, across education and service delivery, so that learning in the classroom is not lost in practice.
  
- Further research is needed to explore the impact of consumer involvement in education and training on students' attitudes, behaviour and practice, and to compare different ways of involving consumers (in different aspects of education and training and at different levels of the organisation) to identify those having the most extensive and enduring impact.
  
- Research is needed to track the development of organisational consumer involvement strategies 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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## BACKGROUND

The importance of involving consumers in all aspects of health care began to permeate government policy in the 1980s and was firmly ensconced in health policy by the '90s. The Community Care Act (1990) clearly placed consumerism 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 (see, for example, 'The New NHS: Modern and Dependable [Secretary of State for Health 1997]; 'A First Class Service' [DOH 1998]; 'Patient and Public Involvement in the New NHS' [DOH 1999]; 'The Expert Patient' [DOH 2001]; and the different National Service Frameworks).

This has resulted in the development of structures for consumer involvement within services (for example the development of Patient and Public Involvement Forums (PPIF's) in every NHS Trust to seek the views of patients receiving services [DoH, 1999]), in research (for example ethical committees are not merely concerned with protecting patients involved in research but require evidence that consumers have been involved in the development, implementation and dissemination of research projects [DoH, 1998]) and in education, where educational institutions are required to involve service users and carers when designing and delivering training programmes (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]).

In response to policy requirements for healthcare education, educational institutions and workforce confederations have been developing guidelines for involving service users and carers in education training. The Northern Centre for Mental Health, funded by NIMHE (National Institute for Mental Health), produced a tool to help Workforce Development Confederations to audit user and carer involvement in higher education and inform the commissioning of post-qualification mental health education programmes (NCMH 2003). An integral part of the tool is the adaptation of the 'ladder of participation' offered by Goss and Millar (1995). This comprises five levels ranging from: 'no involvement' at level one; through 'passive involvement' (e.g. consultation with users via a third party); 'token involvement' (e.g. consultation with users through non decision-making forums); 'collaboration' (e.g. users' views form basis of decisions) to level five - 'partnership' whereby 'educationalists and users work together systematically, strategically, with full support, reimbursement structures and with education and training opportunities available' (NCMH 2003 pg 34).

Tew et al (2004) present an assessment tool for Higher Education institutions to be used in conjunction with the above tool. They suggest that educationalists/course leaders may not always be in a position to advance in isolation and there may be a need to address some of the issues through joint strategies

involving education providers, service providers, user and carer organisations, Workforce Confederations and NIMHE Regional Development Centres. Therefore this tool includes assessment of user/carer preparation (e.g. training, support and supervision) and remuneration (including the infrastructure for employment or contracting) as well as scope of involvement and inclusiveness of the course culture. At least two Universities (Dundee and Central Lancashire) are developing School-Wide strategies for consumer involvement in all aspects of course staffing, planning, development, delivery and evaluation.

Yet, although consumer involvement in education and training is increasingly recommended/required, and guidelines for good practice exist, 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.

## **AIMS OF REVIEW**

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:

- the different models/approaches taken to involve consumers in the education of health professionals;
- the methods used to evaluate these projects;
- the advantages, disadvantages and impact of different models/approaches in terms of process and outcome;
- potential ethical implications/dilemmas
- an analysis of progress made and gaps remaining in both practice and research.

## METHOD

### Search Strategy

A variety of search methods were employed to ensure all the relevant literature was identified. The major health and social science databases searched were: Cinahl, Medline, Assia, PsycINFO, British Nursing Index, Social Science Citation Index. No date restrictions were placed on the search other than those defined for each database. Citations were followed up from reference lists and bibliographies from retrieved articles. Relevant websites were consulted (including, for example Australian National Resource Centre for Consumer Participation in Health (NRCCPH), Consumer Focus Collaboration Publications, INVOLVE, DoH website, National Research Register), 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:

- 1 exp \*education, medical/
- 2 exp \*education, nursing/
- 3 exp \*teaching/
- 4 learn\$.ti.
- 5 teach\$.ti.
- 6 taught.ti.
- 7 course\$.ti.
- 8 module\$.ti.
- 9 or/1-8
- 10 ((consumer\$ or user\$ or patient\$ or client\$ or lay or carer\$ or public) and (involv\$ or particip\$ or collabor\$ or consult\$ or partner\$ or advoc\$ or opinion\$)).ti.
- 11 exp \*consumer participation/
- 12 or/10-11
- 13 9 and 12

No date, language or study type restrictions were applied at the searching stage. Retrieved references were imported, using relevant key words, into a Reference Manager (Version 10) database.

### **Inclusion and Exclusion criteria**

All papers describing a study or project in which consumers were involved in education and training of health care professionals were retrieved. At this point, no judgement was made about the quality of the initiative/research.

Papers were excluded if they referred to consumer involvement in the education of other patients (e.g. through expert patient/peer education initiatives, or provided a commentary or opinion on user involvement rather than focussing on a specific initiative/project.

Initially, over two thousand citations were identified, these were sorted by both authors, who separately marked papers that were considered relevant, based on the abstract. A very high level of agreement was achieved, both authors selecting 210 papers in common, and a further 5-6 papers that differed. All marked papers were retrieved in full and read separately. Many of these referred to projects in which patients were educating other patients. It was eventually agreed that 38 papers met inclusion criteria for the review and several others provided relevant background information. These 38 papers varied in client group, student group, nature of initiative and formality of evaluation as shown in Table 1.

It is worth commenting on this inclusive approach. Systematic reviews of high quality research evidence have been conducted to discover conclusively 'what works for whom'. In such studies rigorous inclusion criteria are essential to allow meta-analysis of cumulative findings. Yet such a systematic approach is not appropriate for the present review which seeks to explore broader questions about user involvement; not so much "what works" as "what sorts of approaches have been developed" and "how can/should we judge whether it works". User involvement is not a highly defined intervention so it does not lend itself to research through randomised controlled trials; neither does it lend itself to replication: much will depend upon the individuals involved, the nature of the education and training initiative they are involved with, the aims of the programme and so on. It is therefore not surprising that none of the papers retrieved in this review report randomised controlled studies nor any purely quantitative studies.

Once a review extends its scope beyond randomised control trials, the assessment of the quality of the evidence inevitably becomes more complex and more reliant on informed researcher judgement (Murphy et al, 1998). This is particularly challenging where a wide range of research methods and approaches encountered. A number of authors have advocated the use of Systematic Reviews to synthesise qualitative research (e.g. Blaxter, 1996; Popay et al 1998). Taking the principles of traditional (quantitative) systematic reviews, this involves appraisal of each piece of literature to ensure that conclusions are based on what is judged to be the highest quality research evidence. There

are a number of questions that can be asked to help judge the 'validity' and 'reliability' of much qualitative research (see Popay et al 1998; Mays and Pope 2000), but these have drawbacks in the present context.

First, there is no commonly accepted hierarchy of process or evidence in qualitative research - the reviewer must ultimately make a judgement about inclusion. Second, adherence to any given checklist runs the risk of underestimating the usefulness of evidence that can be yielded from literature of a less rigorous methodological quality. Quality criteria are not, therefore, used primarily to exclude poorest quality evidence, but to assess the strength of evidence and the weight that findings should be given in the synthesis and conclusions of the review (Mays and Pope, 2002). Third, methodological appraisal is often restricted by the type of journal that articles are published in. Professional journals often place an emphasis on implications for clinical practice rather than the research methods employed. Therefore a rigorous methodology may have been utilised, but authors have placed an emphasis on results rather than method, and accessibility to practitioners rather than the acceptability to peer reviewers required in research (academic peer review) journals. As Popay et al state (1998, p.344) "reports, articles and books rarely provide enough detail of the methods used for an adequate judgement to be made about the quality of the study being reported". This is perhaps even more pertinent in a review of user and carer involvement since reports and papers written by consumers are less likely to achieve publication in peer reviewed academic journals, and until recently were rarely seen in professional journals. Such accounts provide valuable evidence based on the 'expertise of experience' of using services, suffering from particular illnesses, being on the receiving end of professionals' administrations, but they are rarely written within a professional paradigm and many would not meet given criteria for assessing the quality of research.

The search for a standardised "all encompassing critical appraisal check list for qualitative research may be neither appropriate nor possible" (Greenhalgh 1997). Jones asserts that "the rush to imitate quantitative procedures is producing a kind of "mission drift" in many qualitative systematic reviews" Jones (2003 p1). He advocates a more narrative approach to qualitative systematic reviews in line with the qualitative paradigm. This is the approach taken in the present study.

### **Analysis**

A systematic approach was taken to organise the data (i.e. the 38 selected studies). First the overarching subject covered in all papers was identified: all described an approach to involve service users or carers in a health training and/or education initiative. Therefore the first level of analysis comprised a description of the various models or approaches used in consumer involvement. Secondly, issues related to the process of consumer involvement were identified across all the papers (such as ethical concerns, implications for training consumer-trainers). Thirdly ways of evaluating

consumer involvement were evident through the literature and these provided a further data category. Following a descriptive review of the data falling into these categories, papers were examined to identify systematic relationships and themes in the process of consumer involvement training (e.g. the advantages and disadvantages of different approaches), the outcome (e.g. the extent to which programmes met their own goals) and the philosophy of user involvement (e.g. what are the aims of the initiatives; to what extent is consumer involvement in training seen as a vehicle to change culture and practice?).

## FINDINGS

The selected papers varied in focus, detail and quality (see Table 1). The majority of papers (31 out of 38) described individual educational initiatives that involved service users, placing an emphasis on the process of involvement rather than the effect that consumer involvement has on the training provided, its impact on students' knowledge, skills or practice. Indeed many authors defined the aims of the project as "involving service users in medical/nursing education" with no reference to their reasons for doing this. Approaches to user involvement included:

- consulting with existing user groups for advice, teaching resources/personnel
- creating a reference group of service users or carers to inform education curriculum/ and content
- surveying the views of service users about what should be taught
- service users producing learning materials
- users as teaching "aids"
- users as teachers and assessors

As expected, no systematic reviews of the literature on user involvement in education and training were located and only seven papers reported evaluations of consumer involvement including:

- two studies using a multiple method case study approach to evaluate the process of user involvement in local training initiatives;
- three studies using qualitative approaches to evaluate the experience of users teaching in the classroom from the perspectives of students and the user-trainers;
- two studies evaluated the effect of user involvement on student learning using a comparison, before and after questionnaire design.

### **Advisory Groups for Education**

One way of including the users' perspective in education is by means of patient advisory groups, which can be through targeted consultation (e.g. Greenfield et al), by forming a specific reference group for the purpose (e.g. Ingham 2001), or through a conference set up to consult a range of interest groups (e.g. Harrison and Beresford, 1994 ).

Harrison and Beresford (1994) describe the use of a conference as a means of consulting with a range of different consumer groups in order to inform social work training for CCETSW. The conference proved an effective means of eliciting the views of service user groups about what the process of user involvement should be. Key points to emerge from this exercise included: the need for adequate

resources; the importance of involvement throughout training; the need to increase recruitment of users to professional training courses; the potential for service user involvement to increase the knowledge base for training and education; the need to represent diversity; the importance of enabling service users to make a wide contribution to the training – not restricted to simply discussing ‘being a service user’, and the importance of including new emancipatory approaches to research in research teaching.

Iskander (1999) draws on her experience of consulting an established consumer group, a self-help organisation called SANDS that supports families when a baby dies. SANDS developed national guidelines for professionals on managing miscarriage, stillbirth and neonatal death based upon the experiences of families. Iskander concludes that much can be learnt through consultation by means of a conference attended by all relevant parties.

Two papers discuss the process of forming reference groups from existing consumer groups (Ingham 2001; Sawley 2002). Ingham (2001) describes the setting up of a reference group for the specific purpose of providing the user perspective to inform a new pre-registration course in Northampton. Recruitment for the group was coordinated through the local health authority and members were drawn from a wide spectrum of patient and voluntary service groups. Like the CCETSW conference, the reference group addressed the process of involvement, but in this case, it identified ground rules for patient participation with implications for both the involved consumer and the educational organisation. It recommended that: user participants should be briefed; 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; care, good manners and hospitality needed to be demonstrated by both the organisation and the individual lecturers; practical information should be conveyed by means of a standard information pack; the organisation must inform the user who recommended them; the user should be provided with support, feedback and access to further counselling following participation; patient contributions need to be guided, and student questions may also need to be guided to protect the user from ‘no go’ topics; and access and remuneration requires consideration.

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 via a variety of routes: - a list of charities provided by the local community health council; notices put up on children’s wards; personal invitations sent to parents who nurses thought might be interested; and by various media outlets. 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. These centred on family-centred care, communication and assessment. The most

surprising revelation for the author of this paper was that families disliked family centred care – an ethos that underpins modern children’s nursing. However, on further examination it was discovered that it was the lack of explanation to parents that was the problem rather than the actual philosophy itself. As a result, this initiative did not only influence educational courses, but led to practice development within the Trusts and more effective networking.

Greenfield et al (2001) were also interested in accessing views in order to inform curriculum content, in this case medical training. However, they specifically required information on how future doctors could best serve diverse communities and so rather than access consumer groups as in the above examples, the study approached 12 established community groups representing the various religious and ethnic communities and each group nominated representatives from which discussion groups were formed. Discussions lasted between 60 and 90 minutes and focussed on a single open question: ‘what should future doctors learn about people of (relevant group) origin and their health and health care needs?’ The groups identified 15 themes that the researchers grouped within three broad headings: perceptions of the ‘differences’ in social and cultural beliefs and behaviours of their individual community (e.g. health beliefs and practices, stigma and taboos, life events, diet and use of medicines); the characteristics of a culturally sensitive doctor (e.g. professional behaviour, social and political and economic status, language and communication); and recommendations for medical education (e.g. medical students learning some elementary phrases of greeting or culturally specific behaviours such as a handshake, and examination of racist attitudes). Changes were made to the curriculum content as a direct result of this study and these were fed back to the community groups.

Interestingly, all four papers describing the use of advisory groups differed in both method and findings. Conferences provide an effective format for bringing together views of a range of interest groups around a particular question. Yet the differing emphasis in the findings of the CCETSW conference (resulting in guidelines for maximising the contribution of consumers) compared with the findings of the reference group to inform pre-registration nurse training (resulting in ground rules to protect both consumers and educational providers) perhaps illustrate the influence of the strategy to recruit members and the philosophy of facilitators. As Sawley (2002) and Greenfield et al (2001) illustrate, focussed discussion groups with targeted consumers are an effective way of drawing on specific expertise and experience to directly influence curriculum content. What is not apparent from these reports, is how this content was taught and what impact it had on practice. It is also noteworthy that these papers did not mention support for involved consumers, or payment.

## **Consumer Views on what should be Taught**

Three studies report consumers' views about what healthcare workers should be taught. All focused on service users' views about the training needs of mental health nurses (Mansfield et al 1982; Rudman 1996; Forrest et al 2000) and the common finding was service users' emphasis upon the humanistic qualities of caring and respect, and the importance of interpersonal skills.

An early American study compared the priorities of mental health professionals and consumers with respect to educational objectives (Mansfield et al 1982). Data was collected via a card sort method. Four decks of cards, one for each group represented – consumers, nursing, social work and psychiatrists, each comprising 100-200 educational objectives, were ranked in order of importance by each individual group. The top priorities of the practitioners were therapeutically orientated (e.g. concept of stress, assess client's needs, goals and motivation, termination of relationship, skill in eliciting client's perceptions and capacity to form a therapeutic relationship) whereas the consumers' priorities were more humanistically orientated (e.g. respect, patient rights, women's needs, stress, changing roles, and the need for mental health professionals to be aware of their own value conflicts). However, the consumers also placed high importance upon nurses being skilled in recognition of symptoms and early intervention - skills which would enable patients to have more control of their own difficulties, and thereby more control over their lives.

Rudman (1996) collected data from two mental health user groups (20 service users in total) by means of semi-structured group interviews addressing four key questions: 'what knowledge do you think mental health nurses should possess?; What do you think mental health nurses ought to do effectively?; What qualities do you think are important in mental health nurses?; Is there anything else you would like to say about how mental health nurses are trained? The themes that emerged were grouped within the headings of knowledge, skills and qualities, but again they leaned heavily towards the humanistic and interpersonal side of care. The user groups felt that mental health nurses should know about individual differences, avoiding narrowness, understanding but not labelling behaviour, life/maturity, local areas and resources, the effects of hospitalisation and physical care. The skills that the users found important were counselling/meaningful dialogue, sensitivity to non verbal cues, accepting people's experiences, inspiring confidence, avoiding jargon/stereotyped responses, giving information openly, continuity of support, renouncing own worries, ability to take control when needed and sensitive defusing of tense situations. The users felt the essential qualities of mental health nursing to be: caring: maintaining caring despite socialization; approachability, immediacy and presence; professional demeanour.

Forrest et al (2000) also aimed to elicit user views about the knowledge, skills and attributes they considered that mental health nurses should possess but in addition their study explored strategies for user participation in the ongoing curriculum design and delivery. The researchers collected data by means of five focus groups comprising 34 mental health service users who were recruited with the help of advocacy workers and a drop in centre. Once again, the service users valued human qualities above professional skills. A 'good' nurse was described as someone with 'common sense', warmth and sensitivity, as being nice and someone who can be a friend. Many users in the study felt that existing nursing courses are counterproductive with respect to the qualities they value due to the emphasis upon the professional qualities and the medical model. This could be considered an issue of conflict. However Forrest et al (2000) suggest that, it is more helpful to view it not as a dichotomy but as a continuum with 'human' qualities at one end and 'professional' qualities at the other. They contend that nurses are able to possess both human and professional qualities simultaneously. Whilst there are no details of how the users' views have contributed to curriculum content Rudman (1996) and Forrest et al (2000) claim that the data collected has been used to inform the curriculum and that it is work in progress.

The fourth study in this category presented a discussion on the *process* of seeking user views on what should be taught on educational programmes for cancer nurses rather than the outcome of the consultation (Flanagan 1999). Individual carers, clients and parents of children with cancer were co-opted on to the programme design team which met at formal meetings over the course of several months during which curriculum ideas were discussed, written and refined. The benefits of undergoing this process were reported as: the curriculum was grounded in the reality of human experience; it offered prospective students the possibility of learning 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. However, there were also some learning points. On reflecting on the process it was felt that more could have been done to prepare the service users and carers, which perhaps should have included a formal induction to their role. In addition the importance of ongoing support for consumers was noted, to ensure that any discomfort is addressed. Finally, whilst the design team tried hard to avoid using jargon in keeping with suggested good practice, they found this difficult at times.

Overall, it is perhaps significant that mental health service users have been consulted for their views more than users of other healthcare services. Whilst they place a clear emphasis on the interpersonal skills of nurses, it cannot be assumed that people using other health care services would have the same priorities: more research is needed into their views.

## **Producing Learning materials**

Three papers focused upon service users' involvement in producing learning materials. Coupland et al (2001) describe the process of making a video to demonstrate using a specific psychiatric assessment tool. The inclusion of service users instead of the normally used pseudo patients provided the opportunity to include the sociological and personal aspects of a person's mental health problem rather than just the psychological. The safeguards of consent and back up counselling and support were attended to, but service users found the assessment tool demanding and being filmed was an additional stressor. On balance however, they wanted to take part and students found their involvement helpful.

Sybil Ah-mane also describes making a video for use in the training of mental health workers (Ah-mane 1999). Ah-mane initially trained as a mental health nurse but was admitted to a psychiatric ward before qualifying. The idea for a training video came whilst she was undertaking a project for her degree. She later collaborated with an occupational therapist with the experience of hearing voices to produce a training package 'Learning from Psychosis' which, along with the video, also includes experiential exercises and evocative artwork. They also give participants opportunity to ask questions about their experiences.

The service users in both of these studies found the experience positive. Ah-mane found producing the materials refreshing and therapeutic experience whilst the users in Coupland et al's (2001) study felt empowered and valued with increased self esteem. However, the experience of the service user in the third paper (Reynolds and Read 1999) appears more complex and ambiguous. They describe the process of producing learning materials aimed at providing Open University students, undertaking an undergraduate or diploma course in mental health, with the opportunity of including the perspectives of users and survivors in their learning experience.

A decision was taken early on in the writing of the course that considerable space would be allocated to personal accounts written by mental health service users. They therefore asked a prominent member of the survivor's movement (Jim Reynolds) to become involved. He thought this a good idea but was dismissive of a further idea of juxtaposing these accounts alongside professional accounts within the same publication. He pointed that his that this would lead to the discrediting of the users' accounts. However, the course team (who continued to meet without service user representation) decided to press ahead with this idea. Jim Reynolds reaction to this shocked many of the team members with respect to his strength of feeling about the issue as well as his unequivocal assertion that he would have nothing to do with such a publication. In addition, the way that the course team had excluded the service user from decision making mirrored his experience of exclusion from decision- making during his time as a patient. Some of the academics involved appeared genuinely

perplexed by this turn of events as they felt that they were only maintaining balance. They did not seem to accept the point that Jim had made with respect to power imbalance and credibility.

Once again, it is of note that all reported examples of user involvement in the preparation of learning materials have taken place in the area of mental health. This inevitably incurs issues that may be specific to mental health and cannot be assumed to exist in other areas of health care. (For example, people with mental health problems may be more sensitive to the stress involved in making a film; their views may be more likely to be discounted or over-ridden). Nevertheless, given that most educational courses for health professionals are delivered within higher education institutions, the issue of roles will need to be addressed if user involvement is to be fully embraced. The perception that service users' views need to be balanced, clarified or corrected by professionals needs open and full debate as part of the training and development of educationalists in the era of consumerism.

### **Consumers as Teaching Aids**

Three themes emerged in this category: 'traditional participation', 'community teaching' and 'consent'.

#### *Traditional Participation*

Patients have long been involved in the teaching of medical students although traditionally this has been a passive role (Medio and Morewitz 1992; Wykurz 1999; Stacy and Spencer 1999). Two papers focused upon this traditional type of patient participation. Medio and Morewitz 1992 described four categories of this traditional involvement: - bedside teaching rounds; round-table seminars; standardized patients; and the objective structured clinical examination. Bedside teaching rounds provide the opportunity for medical students to practice, and demonstrate their skills in, physical examination and interview technique. These should be structured and include specific learning objectives and key teaching points. Round-table seminars aim to complement bedside teaching by enabling the students and supervising doctors to discuss the examinations in more depth including the communication skills of the student and the emotional impact of the illness on the patients. This format allows the student to openly talk through difficult or stressful issues away from the clinical area. The standardized patient can be symptomatic or asymptomatic and provides medical students with the opportunity to learn and practice specific techniques of examination (the example given is that of being able to distinguish the different pulmonary sounds within the lungs of a standardized patient with chronic obstructive pulmonary disease). Objective structured clinical examination takes this method a stage further by measuring the clinical knowledge and skills of the student from their

examination of a standardized patient. The assessment is by direct observation of the examination but can include a written examination.

Studies conducted over the past 30 years have suggested a positive response from patients on their involvement in the teaching of medical students (Arnold 1992). One study interviewed 68 patients on medical and general wards following an examination by a medical student to ascertain their perception of their experience and motivation for taking part (Mayo-Smith et al). The students spent 1 to 2 hours performing a complete history and physical examination, which is followed by a review of the case with their preceptor, the attending doctor. The patients were interviewed using a standardized questionnaire and, using a 5-point Likert-type scale were asked to rate the importance of five potential reasons for participating in the examination. In addition the various components of the experience were assessed as well as the willingness of the patient to participate in future such teaching exercises. An open-ended question inviting comments about the experience concluded the interview.

The reasons for taking part that rated the most highly were that of “It may help other patients in the future” and “I wanted to help the students in their training”. Rated much lower were the statements “I thought I would enjoy talking to someone” and “I thought it might help my medical care”. Rated lowest of all was “The doctors might not like it if I didn’t agree”. With respect to the experience the patients as a group did not find it tiring or disruptive, did not feel they had had too many examinations, and rated the overall experience very positively. The final open ended question in each interview produced responses covering: - positive comments relating to the personal and interpersonal characteristics of the students; views that it had been a learning experience for the patient, in terms of what they had learnt about themselves and what they had learnt about medical examination process; satisfaction about helping the students; and a good way of passing the time. Apparently there were only three negative comments which all related to the unexpected length of time that the examination took.

### *Community Teaching*

It is contended in the literature (see for example Wykurz 1999 and Stacy and Spencer 1999) that this traditional role of patients in medical training is passive. However, Medio and Morewitz (1992) suggest that the role can be more active. They contend that for bedside teaching to be an effective learning experience it must include patient feedback, which contains information regarding the patient’s perception of the student’s skills and how they feel physically and psychologically. Another example is that visiting speakers to round-table seminars can include current or former patients talking about what it is like to be a patient or family members of someone who has recently died. Nevertheless there is a strong assertion in the literature that a move towards community teaching and the advent of patient partners in the U.K. has enabled the patient to take a more active role in the

training of medical students. The impetus for this innovation came from recommendations of the General Medical Council in *Tomorrow's Doctors* (GMC 1993).

Community teaching or 'patient partners' differs from the traditional scenario of medical students observing a General Practitioner consultation in that patients are recruited to talk to students with the specific remit of teaching them about their symptoms (Dinsdale 1999; Stacy and Spencer 1999; Coleman and Murray 2002). Patients are partnered with single or pairs of students over an extended period of time (commonly six months) and teach them about their condition, including symptoms and consequences of their condition, without the mediation of a professional tutor. Five papers focused upon patient participation in community teaching.

Two studies carried out qualitative semi-structured interviews with patient partners to elicit their views of taking part in community teaching (Stacy and Spencer 1999; Coleman and Murray 2002). Stacy and Spencer (1999) interviewed 20 patient partners taking part in a community based medical student project in Newcastle with the aim of eliciting perceptions of their role in the programme. The project extended over a six-month period, during which the students visit the patient several times, in pairs. A one in four random sample was taken from a list of seventy-eight patient partners. The interviews were recorded and analysed from the transcripts using a grounded theory approach and emerging themes identified the following teaching roles for patients: 'patients as experts' whereby patients taught the students different aspects of their condition ranging from talking about the experience of the illness and health care provided or their feelings of being disabled and the ways in which they coped, to providing technical descriptions (e.g. details about the situation of a pacemaker) and demonstrating the resulting functional impairment; 'patients as exemplars of their condition' provided students with the opportunity to learn from talking to someone about the broad social and psychological aspects of their condition; and understanding that the same disease can manifest in different ways; 'patients as facilitators of the development of professional skills and attitudes' describes a more passive role and is comparable with the bedside teaching round outlined by Medio and Morewitz (1992) in that it involves the student learning by interviewing them, taking a history and generally developing their bedside manner. It is interesting to note that these benefits of the process are entirely based on the patients' perceptions, the views of students or course leaders were not reported.

In this study Stacy and Spencer (1992) also reported patient's views of how they had benefited from participation: through talking; through learning about their condition; learning about the training of doctors; by helping students' learning; and, by feeling useful in providing practical help to students. The authors acknowledged some of the difficulties posed by this approach, including the need for adequate information about the project, and the fact that a minority of patients felt that they may have

been exploited rather than empowered when students were perceived as patronising or refused to disclose their written notes.

Coleman and Murray (2002) recruited 15 patients involved in community-based teaching across four General Practices with the aim of eliciting their views on the positive and negative aspects of patients participating in the community teaching programmes. Data was collected by means of semi-structured interviews and analysed using a thematic framework. The strongest theme to emerge from the data was that the respondents felt extremely positive about the teaching and, given the opportunity, would be willing to participate indefinitely. The two main motivations for taking part were altruism and personal gain. Altruistic motives included: providing a service to the community through training better doctors; repaying the system (the NHS as a whole as well as their individual doctor); and providing a service for no financial reward. Personal gain included: improved knowledge about their disease and condition increased confidence in coping skills; enhanced self-esteem; relief from social isolation/opportunity for companionship; reassurance of well-being by having thorough examination; a perceived better service; and an anticipated better service. However, whilst the bulk of the views were positive the patients also expressed some concerns, which included embarrassment and anxiety (particularly during intimate examinations); and consent and confidentiality: patients were not clear that their consent to see students also covered consent for students to have access to medical notes. These themes show similarities with the findings of Stacy and Spencer (1992), again, they are based on the perceptions of patients rather than those of students or educators.

Dinsdale (1999) describes the experience of patient partners from the perspective of both partners, the nurse and the patient. The nurse involved believed that *'any idea that encourages better communication between people with arthritis and those caring for them has to be a good thing'* (Dinsdale1999) However, she went on to stress the importance of selecting the patient with the right qualities such as being fairly self confident, as it can be quite daunting talking to a group of health professionals. The patient had been anxious about the role but felt very positive about her involvement as it gave her a new sense of purpose and sense that she is better able to take control of her own condition.

One nursing study also looked at role of clients in student learning in the clinical area (Twinn 1995). The aim of the study was to investigate the clients' perception of their role in student learning as well as the assessment process. The research design was a case study approach employing both qualitative and quantitative methods, the focus of which was one cohort of health visitor students. The sample of 24 women clients (out a possible 33) was selected opportunistically via nominations from Community Practice Teachers (CPT's). Analysis uncovered three main themes. First, 'client's role in student

learning' including providing an insight into the reality of practice, bridging the practice theory gap, providing an opportunity to practise skills and developing relationships with students. Second, 'clients' perceptions of the students' roles in the practicum', this ranged from that of practitioner to absolute student. The author suggests that this reflects the complexity of health visitor students, as with other post basic training, in that some have considerable practical experience in other fields of nursing. Third, 'clients' perceptions of the process of assessing student performance', this illustrated further ambiguities. For example, some female clients felt that they were better placed than some health visitors to say what a good health visitor was, whilst others stated quite specifically that they were unable to assess levels of performance since they were unsure of the 'qualities that the authorities were looking for'. Further ambiguities related to the skill of the student. Few had concerns of assessment when the student was considered to be good but the clients had difficulties if the student was not performing well.

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?* *Who?* serves as a reminder about the diversity of the patient population. *How?* refers to the context, role and type of interaction. *What?* looks at the content of interactions, and *Where?* – refers to the location of the interaction (e.g. hospital/community, service setting/educational setting).

Whilst this framework provides a useful starting point, the findings of the studies above indicate other issues that need to be considered when planning consumer involvement in clinical practice/education. These include ensuring that involved patients are given full information so that they are both able to give informed consent and clear about their role, and their rights (for example to refuse students' access to medical notes, or to refuse physical examination by students). Once again 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 consent. Grant (1994) conducted a small opportunistic survey of opinions with members of the public visiting the Auckland Medical School on an open day. They were invited to complete a questionnaire on 'patient involvement in clinical teaching'. Ubel and Silver-Isenstadt (2000) interviewed a convenience sample of 100 outpatients. The interview began with a discussion, which gave a definition of a medical student and conveyed that, whilst it is necessary for the student to examine patients as part of their training, the patient is under no obligation to comply. This was then followed by a questionnaire which asked a series of questions regarding what procedures the respondents would be prepared to let a medical student do (e.g. take your blood

pressure, do a pelvic examination, make an initial incision for your surgery etc). The patients responded on a 5-point Likert scale ranging from 'definitely allow' to 'definitely not allow'.

The patients in Grant's (1994) study were strongly in favour of taking part in clinical teaching no matter what the setting, with one notable exception, the sexually transmitted diseases clinic. The author discusses this in terms of privacy and embarrassment. The results indicated that, no matter how close the similarities, patients perceive a difference when it comes to the examination of a rash on the forearm as opposed to a rash on the foreskin.

Perhaps as a result of the way that questions were asked, the patients in Ubel and Silver-Isenstadt's (2000) study, appeared to be influenced in their decision of whether to refuse by the type of procedure rather than the nature of the problem. For example the procedures that attracted the highest likelihood of refusal were: 'perform spinal tap'; 'make incision'; 'suture incision'; and 'intubate'. Whilst the procedures that patients were least likely to refuse were: 'take blood pressure'; 'watch surgery'; and 'take sexual history'.

These papers do not discuss the ethical dilemmas inherent in inviting patients who attend a teaching hospital/practice to allow students to observe or undertake a health care procedure. These do, inevitably, exist: people may 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. It would be useful to explore patients' responses and their reasons for either agreeing or not agreeing to student involvement.

### **Consumer Involvement in the Classroom**

Eight papers focused upon involving service users and carers in the classroom. These can be subdivided around the themes of 'established groups', 'individuals talking about their experience', 'users assessing students', and 'barriers to involvement'.

#### *Established Groups*

Rowley (1995) describes the way in which Suffolk social services included the service user perspective in their training programme. Feedback from a mental health service user group asserted that the 'one hour slot' traditionally used, as a method of user participation was inadequate. This led the Suffolk Mental Health Training Group to begin a pilot project integrating service users into professional training as course members. This was reviewed following five courses, which included a total of 12 service users. Overall it was a positive experience for both the service users and the

professionals. It was suggested that it changed their perception of each other, e.g. it broke 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, which made some realise the helplessness of a user with regard to treatment. Nevertheless the evaluation of the course also revealed some limitations. For example, remuneration appeared to be a contentious issue and this seemed to affect the opportunity for some to attend which in turn, some felt, caused an imbalance between users and professionals.

Soliman and Butterworth (1998) describe the involvement of a group of carers in professional education for dementia care. These carers who belonged a group called the Council of Relatives to Assist in the Care of Dementia (CRAC Dementia) became involved in training professionals when one of the authors (Butterworth) was asked to talk to a group of social workers. She decided to take other carers with her and 'the effect was stunning'. The carers spoke from the heart and the social workers really appreciated the knowledge this helped them to gain. This appreciation was disseminated and further such invitations escalated. The carer group now occupy regular slots on local nursing courses and have also spoke on medical training courses. The students and professionals on the courses have repeatedly expressed their appreciation to the carers and have indicated to them just how much knowledge and understanding they have gained from listening to their personal experience. This has resulted in the carers feeling that their contributions are of value and importance.

The Wiltshire User Network also became involved in training professionals from a small beginning (Evans 1994). The Network came to professionals' attention through involvement in the care management process. This led to their request for a consultation meeting during which the users expressed their anger about inappropriate aspects of the required assessment form and about the lack of user involvement in the design process. From this meeting came a growing understanding between both users and professionals about the value of collaborative working and the Network were invited to participate in a 24-hour seminar alongside a representative from social services and the Health Authority. As with Soliman and Butterworth (1998) opportunity to be involved in training has escalated and they are now involved in a range of sessions covering a variety aspects of care management. This includes having an influence upon the whole process for example the design of referral, assessment and care-plan forms and the recording of unmet need. In keeping with Soliman and Butterworth (1998) the professionals have recognised the value and contribution of users' expertise. Users have particularly valued the opportunity to challenge professionals to work in more empowering ways. In addition the experience has led to the empowerment of users in their own organisation to act as agents of change.

In all of these examples, it was the user group who led developments in their own involvement; they grasped opportunities to make their voices heard and their value was recognised by professionals. No mention of payment or support for speakers is made in these papers.

#### *Individuals Talking about their Experience*

The individuals in both the following papers were picked because they were considered by the educators to be experts in their own lives and conditions. Hutchings (1999) describes the experience of involving one patient, with multiple sclerosis, in a specially created forum in order to present his perspective and experience to his unit's nursing staff. The patient, who is referred to as K, held a doctorate in psychology, had counselled people with long-term health problems for 20 years, was resonant with the available literature in this area and explored relevant web sites. The author reasoned that, given his substantial personal and professional knowledge and experience, K was the unit's greatest untapped resource. K co-facilitated a presentation at the forum with Clinical Resource Nurse (CRN) focusing upon the physical and psychosocial implications of MS. K covered the areas about which he had unique expert knowledge, that is, the emotional, psychological and social consequences of MS, whilst the CRN prepared material that could be drawn from research, e.g. the physical implications.

The forum was well attended, by nurses who were off duty as well as on, and included some of K's own caregivers. K's account of his experience appeared to be well received. The nurses continued to ask questions long after the presentation had finished, two even following him to his room for further discussion. An interesting outcome from this presentation is that it seemed to mark the beginning of a subtle shift in K's relationship with the nursing staff. The nurses began to see K as the expert which, Hutching's argues, shifted 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 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*

There are two papers that present examples of service users assessing students. Frisby (2001) describes the involvement of mental health service users in the formative assessment of students undertaking a pre-registration mental health nursing course by means of client review presentations. These presentations last 45 minutes each and focus on one specific aspect of a mental health client's

assessment (e.g. risk, mood, behaviour, thoughts, and social skills). The presentation comprised a role-play followed by structured reflection in which the student was helped to explore the dynamics of their client assessment by user representatives, lecturers and fellow students. Both users and students viewed this experience positively. Service users reported a feeling of empowerment and encouraged their colleagues to become involved. The students felt that user involvement enabled them to get a deeper understanding of how their interventions have a real effect on clients' issues by listening to the voice of experience. However, they also felt that sometimes the user's contributions were a bit biased towards a non-accountable position, which, if carried through, might reflect unethical practice.

Frisby (2001) argues that to promote legitimate partnership and engagement, it is necessary to liaise with user groups from the beginning in order to establish an agreed and shared agenda. In this case it enabled preparation and planning prior to the sessions and also allowed discussion regarding issues of concern about the client review format. Areas that also became potential causes for concern were possibility of users being required to revisit distressing experiences and the issue of professional accountability. He provides an example that illustrates both these aspects. The right of patients to commit suicide was advocated by a service user but challenged by a lecturer on ethical grounds. The service user subsequently talked about his own suicide attempt and revisited the feelings around this event. Frisby (2001) 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 tokenist compliance.

Cole (1994) describes the experience of a group of service users who became involved in assessing 11 social workers during their learning disability placement. The seven service users were all council members of Chelmsford Training Centre who became part of the teaching team at Anglia Polytechnic University, working alongside a lecturer and their facilitator from the training centre. The experience is told through the voices of the service users. The service users attended the University to conduct the assessments which involved the students and service users asking each other questions. At the end of each interview the users allocated marks although it is not clear whether these formed part of summative assessments or were for formative purposes only. Service users found the interviews a rewarding and beneficial learning experience.

### *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. Whilst four out of the five lecturers generally considered user involvement to be a good thing their subsequent contributions suggested ambiguities. One lecturer felt that nothing could be gained from educationalists developing a relationship with service users, but acknowledged limited knowledge

about user participation in education due to the lack of research in this area. Respondents were not clear about the advantages of user involvement in education, but they were aware of potential disadvantages. They were concerned that the attributes of someone who was mentally ill would prevent them from being able to teach groups of 60 student nurses. Their views were that if a service user was able to overcome this obstacle then they were not representative of the core group of users and therefore not meeting the requirements of user participation, thus indicating a kind of ‘catch 22’ situation. Furthermore, lecturers did not want the service users to become professionalized; they wanted their role as patients maintained as this was perceived as more useful for participation in the programme. Another perceived disadvantage for the users becoming professionalized was an erosion of their own roles into that of ‘glorified markers’.

Felton and Stickley (2004) found that an inequality of power between service users and educationalists was apparent throughout the participants’ discussions. They argue that professionals may be reluctant to hand over some of their power until they can see the advantages of doing so. This confirms the need for ongoing development of teachers through training, clinical practice and exposure to contemporary debate.

### **Evaluations of consumer involvement**

Seven papers presented evaluation studies, which can be subdivided into the themes of: ‘evaluation of the process of involvement’, ‘evaluation of teaching in the classroom’ and ‘evaluation of the effect of user involvement on students’.

#### *Evaluation of the Consumer Involvement*

Two papers reported evaluations of the process of involving service users in education; both were concerned with education in mental health. Barnes et al (2000) used a case study methodology to evaluate a post-graduate programme of interprofessional education in community mental health. Methods of data collection included an analysis of documents concerned with the tendering, both to provide the education programme and to conduct its evaluation; interviews with key participants including user representatives; a survey of user groups; and group interviews with participants in the first two years of the programme.

The educational providers were able to demonstrate a number of ways in which service users are involved: as members of the programme management board; reviewing the curriculum; contributing to teaching sessions, both individually and collaboratively; by students inviting service users to attend two of the modules in the first year to demonstrate multi-disciplinary working; and one user took co-

responsibility for co-coordinating a module which involved selecting reading materials, marking assignments and reviewing and planning.

This paper also described the development of a questionnaire to assess 'added value' for service users which could be attributed to the programme. A questionnaire comprising user-developed outcome indicators was verified by a second user group in the West Midlands (the location of the programme) and then sent to all user groups in the West Midlands. The outcomes that service users prioritised included: students should demonstrate understanding, and not just try to solve problems or push people into services; students should treat service users with respect, not as labels; first and foremost, professionals should develop their capacity to 'be human'; students should have knowledge about services, including advocacy services and service user groups; and, students should be able to provide information about how to involve service users in assessing their needs. Overall, Barnes et al (2000) found that, whilst users' contributions were valued, they were not given the same credence by the programme participants as contributions from senior academics from the field of psychiatry and psychology. Nevertheless, where service users have been partners from the beginning, power sharing has been visible (Barnes et al 2000). Yet even where power is shared, roles and responsibilities have been constrained by the formal university requirements for academic programmes e.g. timetables, course approvals, and modes of assessment and degree regulations.

Masters et al's (2002) paper forms part of a larger study, part of which has already been presented in this review (Forrest et al 2000). This part of the study focused upon the evaluation of the project and the evaluation of the strategy document and its implementation, both from the perspective of all the stakeholders. Data was collected by two questionnaires, compiled for the purpose. One questionnaire was aimed at the project members, the other aimed at people who had knowledge and experience of the project but were not members of the project groups. 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 the learning of new skills, increased self-confidence and a genuine feeling of empowerment. However, the main area of tension related to the university lecturers who were not involved in the project and who felt 'left out'. They called for a wider ownership of the project. A further area of concern relating to roles and responsibility was the tension between the 'ideal' of user involvement taught on the course and the 'grim reality of practice'. It was suggested by one of the project lecturers that their role therefore is to support students whilst also getting the 'service side on-board'.

Both of these studies shared the finding 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 constant high levels of energy and commitment (Masters et al 2002) which can be translated as 'added value' (Barnes et al 2000). Without support from the wider university this can put stress and pressure on the lecturers involved. To this end the project members in Masters et al (2002) argued that the appointment of a project development worker was essential for the project's long-term success.

### *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. Each workshop ran for 4 hours and was facilitated by an educator from each discipline (medicine, nursing and social work). During the workshop students worked in small inter-disciplinary groups and in the second half of the workshop each group is introduced to a family carer. The students were then given 30 minutes to elicit the carer's experience using a structured format provided by the facilitators. 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 comprising a mixture of closed and open questions on different aspects of the session and user involvement in nurse education generally. Sixty-seven out a possible sixty-nine 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. The researchers' used a qualitative analysis for the positive and negative statements.

Curran (1997) presents the outcome of a study of which reviewed workshops within the 'Mental Health Area of Particular Practice' programme, validated by CCETSW. The workshops were co-facilitated by an Approved Social Worker, a black mental health advocacy worker, two user trainer consultants (recruited through a user network) and a social work lecturer. The purpose of the review was to move towards a more collective approach and its aim was to look at extending user participation. For this reason the researcher chose an action orientated participatory process as the methodology and individual interviews of all participants (students and facilitators), structured to

focus on the experience of participation in terms of the process and value, as its data collection method. These interviews were then followed up by a three-hour workshop, which led to towards a participatory approach towards the design of the whole programme and proposals for a further workshop to be expended to the whole Social Work Group.

All three studies reported 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. The students felt privileged to hear the carer's story, finding the experience moving, informative and instructive (Turner et al 2000). Students valued the opportunity to empathise and respect 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 and intimated that the answers that real patients gave them were superior to text book ones (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. They handed her a tissue, let her be, and did not appear embarrassed, for which the carer was both grateful and impressed.

The users and carers in the study 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 came from a desire that students understand their perspective in order to improve the service they provide for them and future recipients. They wished to give students the experience of human feelings (Turner et al 2000) and demonstrate their identity as people with many aspects to their lives whilst breaking down stereotypes of passivity and dependence (Curren 1997). Direct participation was considered essential to promote user participation in practice. There were also personal benefits gained from the experience. It felt good to be invited to speak to students; it built up damaged confidence (Costello and Horne 2001). Curren (1997) acknowledged organisational issues emerging from the study such as the need for adequate preparation and sufficient time for the patient's or carer's presentation.

#### *Evaluation of the Effect 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, a local user group was approached to become involved in classroom teaching on the mental health branch of the Diploma in Higher Education and Nursing pre-registration programme. A comparison research design was adopted to measure the effects of the differing exposure of user involvement

between two groups of students within the same cohort. The time period for the study spanned two terms in the second year of a three year programme. Group 1 received user participation sessions in term six, group 2 did not. 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. This consisted of the following: what are the core needs which arise from this interaction? In order of importance please prioritise three needs; what question would you have liked to have asked during the interaction that was not asked?; and please make any further comments on the interaction content. The 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. The study also elicited data through classroom observation and a group discussion. Transcripts were analysed using a thematic content analysis.

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. The study took place within the context of an interview methods course at the end of which the students are required to make a brief video recording of an interview with a real patient and to receive feedback from tutors and peers. Data was collected using two outcome measures: the Attitudes Questionnaire (a 32 item self-report questionnaire) and the Interview Rating Instrument (a 36 item behavioural assessment of students' interview performance). There was a 94% response rate. During their fifth year the students from the first cohort studied were invited back to participate in a follow-up evaluation. There was a 61% response rate to this. Data for both were analysed using parametric and non-parametric tests (*t*-test, U test, kappa and chi-squared test).

The findings from both studies showed marked differences between students who were and were not exposed to students. 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 one were

also able to demonstrate a tendency towards an individualised approach (Wood and Wilson-Barnett 1999).

However, the most marked difference in both studies was that the students in the exposed groups were able to show more frequent and empathic understanding. They were able to show concern about the impact of illness and symptoms upon the patients' lives. The nursing students in group 2 (Wood and Wilson-Barnett 1999) were exposed to service users in term seven (whereas group 1 was not) and the researchers found a levelling off in most of the categories following this. However, they found that empathic understanding and an individualised approach remained higher in the students from group 1 even at the end of term seven. They 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.

### **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 - despite this being identified as important by lecturers (Turner et al 2000; Masters et al 2002) and service users (Curran 1997). 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, this limited or lack of information can result in user and carer participants feeling uncertain about their involvement, not understanding the purpose, and feeling that they lack expertise (Spencer et al 1999; Turner et al 2000; Masters et 2002).

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). Unlike examples above, both preparations were structured.

Gall et al (1984) recruited Patient Instructors (PI) who met the specific criteria (relatively stable, advanced rheumatic disease; maturity; above-average intelligence and verbal ability; outgoing personality; adequate mobility for independent transfer from an examining table; ability to be examined in a reasonable period of time (45 minutes) without undue pain; enthusiasm and ability (in terms of time) to participate; and presentation of physical abnormalities in the musculoskeletal system. Eight patients met the criteria and were selected but two were subsequently dropped because they could not master the vocabulary or the techniques of the physical examination.

In contrast, it was much less arduous for mental health service users to become participants in the training programme reported by Hanson and Mitchell (2001), the only criteria being that they possessed the motivation to use their experiences to help others gain a greater understanding of mental health issues from a user's perspective.

The Patient Instructors' preparation course consisted of at least thirty hours of individualized teaching, using a variety of aids, and covering medical terminology, the anatomy of the musculoskeletal system, and techniques of the physical examination (Gall et al 1984). The preparation for mental health users, however, was more concerned with the techniques for the teaching itself and was based on the ENB998, a teaching and assessing module for nurses, as well as a similar 'users as trainers course' already running elsewhere (Hanson and Mitchell 2001). 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 were invited back for a post course evaluation six months after the course had ended to which four users attended. They all agreed that the course had given them the skills and confidence to become involved in a variety of activities. Two of these had been engaged in classroom teaching for the mental health branch students, one had become involved in a 'patient participation group' for their local Primary Care Group and one had provided advice to student nurses on a placement. Two users who were not there had presented at a School of Nursing conference (Hanson and Mitchell 2001). 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 accounts, views and experiences in teaching sessions; whilst the emphasis of the Patient Instructors' training was more about what to teach 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 taking consumers' views, experiences and priorities into account.

## DISCUSSION

To ensure all the relevant literature was identified a variety of search methods were used and a combination of thesaurus and free text search terms were incorporated. Initially, over two thousand citations were identified which resulted in 216 papers being read. Application of the inclusion/exclusion criteria, (i.e. papers describing a study or project in which consumers were involved in the education or training of health care professionals) resulted in a final 38 papers that formed the main body of this review.

Given the subject matter, the majority of the papers examined were qualitative or descriptive and no paper was found to be exclusively quantitatively based. Traditional analysis was therefore considered to be unsuitable. Instead the analysis for this review was guided by Greenhalgh (1997) and Jones (2003) and involved identification of systematic relationships and themes in the process and outcome of consumer involvement.

The approaches to user involvement included:

- consulting with existing user groups for advice, teaching resources/personnel
- creating a reference group of service users or carers to inform education curriculum and content
- surveying the views of service users about what should be taught
- service users producing learning materials
- users as teachers and assessors.

Out of the 38 papers only 2 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. 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. Research into consumer involvement in the health care education and training is therefore inconclusive.

This review suggests that the response to user and carer involvement by the students, users/carers and, to a large extent, the teachers, is positive. The users' and carers' motivation for getting involved appears to be a desire to improve services for themselves and others and, in some cases, a wish to 'give something back' to services by helping train future professionals. They appear to gain some immediate benefits, e.g. catharsis, further knowledge, an increase in confidence and self worth and a feeling of empowerment. However, this begs the question of whether there are more appropriate ways

of enabling users and carers to achieve these benefits and whether or not this provides a rationale for involvement in professional education.

Students appreciate the opportunity to hear real life experiences which, they feel, enhances their understanding. This may seem surprising when they have the opportunity to hear first hand accounts every day whilst working in practice areas. Nevertheless, there does appear to be a difference. This was particularly illustrated by Hutchings (1999) in that when nurses listened to their patient 'K' in a classroom setting they felt they learnt much more about him and continued to ask him questions once back on the ward. Hutchings argued that a shift in the balance of power had taken place through students recognising the expertise of the patient in a classroom setting where roles were reversed from those in practice: students were the recipients of information and education whereas in practice they perceive themselves to be in the role of information giver. Perhaps further user involvement in training will gradually erode students' expectations that they must be seen as the '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 (one in mental health nursing and one in general medical training) 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 might tentatively suggest 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. Appropriate and adequate payment is important as proper remuneration equates with value, yet very few papers mentioned this and it can be assumed that the majority of consumers involved in consultation exercises and in medical training have not been offered payment. Out of the 38 papers only 5 described how the user/carer trainers had been prepared and yet users and carers, when asked about their concerns about involvement, identified lack of

preparation as an issue every time. 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 generally 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 e.g. allowing suicide) 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 was often cathartic. Such issues need extensive debate with equal representation from consumers and academics/professionals before a true partnership model, as advocated by national guidelines (e.g. NIMHE 2003) 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 or module rather than the product of 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.

## CONCLUSIONS AND RECOMMENDATIONS

1. Consumer involvement aims to change the culture of healthcare so that services reflect the wishes and priorities of people who use services. Consumer involvement in training and education aims to facilitate this process but in itself it is not enough. Therefore:

- *it is essential that consumer involvement is developed in partnership, across education and service delivery, so that learning in the classroom is not lost in practice.*

2. Little is known about the impact of consumer involvement in training and education on practice/service delivery. Therefore:

- *further research is needed to explore the impact of consumer involvement in education and training on students' attitudes, behaviour and practice, and to compare different ways of involving consumers (in different aspects of education and training and at different levels of the organisation) to identify those having the most extensive and enduring impact.*

3. Consumer involvement in training and education is largely limited to one-off courses and modules. A small number of institutions are in the early stages of developing organisational strategies for user involvement and these could provide useful models for the future. Therefore:

- *research is needed to track the development of organisational consumer involvement strategies 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).*

4. Although consumer involvement is generally perceived to be positive and rewarding for those involved, they do need support. Therefore:

- *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.*

**Table 1. Summary of papers reviewed**

Author	Title	Date	Approach to consumer involvement	Type of evaluation	Findings	Learning points
Ah-Mane, S.	'Clinical View'	1999	Service user producing learning materials	Description/opinion piece.	Users' experiences should be given equal priority alongside the currently over-emphasised symptoms and effects of mental disorder.	Users' insights can provide a valuable tool for the advancement of nurse training – yet are not put to use.
Arnold, L.	Commentary on Patient Participation in a Physical Diagnosis Course.	1992	Service users as teaching 'aids'	Commentary	Patients participated for positive reasons: to help students and to help other patients.	It is helpful when there is reciprocity between students and patients.
Barnes, D et al	Partnerships with Service Users in Interprofessional Education for Community Mental Health: A Case Study.	2000	Service user involvement in the development, delivery and evaluation of a post-graduate programme.	Evaluation of process and outcome – utilises a case study approach.	Whilst users' contributions are valued they're not given same credence as academics. Roles and responsibilities constrained by university regs.	User involvement requires ongoing momentum.
Chapman, V.	Consumers as Faculty: Experts on Their Own Lives	1996	Users as teachers	Description	Four user's 'stories' are offered as example	Discussion not included
Cole, A.	'It was and Education'	1994	Users as teachers and assessors	Summary of comments made by user participants	Users found the experience positive and found the assessments to be a rewarding and beneficial learning experience.	Jargon and terminology can be a barrier. Requires commitment from the students.
Coleman, K. and Murray, E.	Patients' Views and Feelings on the Community Based Teaching of Undergraduate Medical Students	2002	Service Users as teaching aids	Qualitative research study focusing upon participant patients' views and feelings.	Patients felt very positive re participation. Reasons for doing so: altruism and personal gain.	Patient concerns included: embarrassment, reinforcing the 'sick role' and student access to notes.
Costello, J. and Horne, M.	Patients as Teachers? An Evaluative Study of Patients' Involvement in Classroom Teaching	2001	Users as teachers	Evaluation of sessions taught by three patients. Methods:- focus group discussion and questionnaires	Students got more satisfaction from listening to personal experiences of the service users than hypothetical ones. Users found it valuable and cathartic.	Involving inpatients in the classroom carries a risk which provides an ethical dimension including the issue of consent.
Coupland, K., Davies, E. and Gregory, K.	Learning from Life	2001	Service users producing learning materials	Description of the process of producing a video	Service users felt empowered and valued with an increased self esteem. Feedback from students good.	Despite safeguards of consent and back up counselling, users found making the video very challenging.

Curran, T.	Power, Participation and Post Modernism: User and Practitioner Participation in Mental Health Social Work Education.	1997	Users as teachers	Evaluation of user involvement in mental health social work course. Data collected by means of interviews and a collective workshop.	Involvement helped users to break down stereotypes of passivity and dependence. Students valued opportunity to empathise and respect user views.	User involvement needs to be positioned within a framework of power. User involvement should move to user participation which should move to user led education. Any risk of exploitation should be addressed.
Dinsdale, P.	Gain from Pain	1999	Users as teaching aids.	Description	Participating patients have become more active, attending meetings all over the country and finding they are able to reduce their medication. Participating doctors feel they have increased their knowledge of arthritis.	Stresses importance of selecting patients who are fairly self confident as it can be daunting talking to a group of professionals.
Evans, C.	The Service Users Who Train Care Managers	1994	Service users as teachers and assessors	Commentary of user group involvement written by the convener of Wiltshire Users' Network.	Value placed upon users' expertise and collaboration has increased to include more workshops and courses. Users found involvement empowering.	Need for valuing users' expertise and contribution by means of a small payment as well as reimbursement of expenses.
Flanagan, J.	Public Participation in the Design of Educational Programmes for Cancer Nurses	1999	Consulting service users and carers re curriculum design and content	Description and discussion of user and carer involvement in designing the curriculum for cancer course.	Benefits of user involvement outweigh any costs. Professionals have real discourse and revealing insights into the feelings of service users and carers.	Issues needing to be considered are: preparation for role; remuneration; use of jargon; and the commitment, energy and stamina required in working with diversity.
Forrest, S. et al	Mental Health Service User Involvement in Nurse Education: Exploring the Issues	2000	Surveying the views of service users on what should be taught	Qualitative research study	Participating service users value human qualities above professional skills and some feel that nursing courses can be counterproductive with respect to this.	A coherent and strategic approach has to be taken to achieve user involvement and cannot just be added to existing programmes.
Frisby, R.	User Involvement in Mental Health Branch Education	2001	Service users as teachers and assessors	Description and discussion of service users' involvement in formative assessment in the classroom.	Both users and students viewed the experience positively. Users felt empowered, students felt they gained a deeper understanding.	Preparation before each session important. Users not bound by same 'accountability' as nurse lecturers. Users may revisit distressing experiences.
Gall, E et al	The Use of Trained Patient Instructors for Teaching and Assessing	1984	Preparing service users to be educators	Quantitative research study. Data collected by means of checklists	Patient Instructors evaluated the project as worthwhile and enjoyable.	For successful involvement there needs to be dedicated medical educational staff

	Rheumatologic Care				Improved performances were indicated for both medical students and physicians.	funded to run such a project and to maintain Patient Instructors' skills.
Grant, V.	Patient Involvement in Clinical Teaching	1994	Service users as teaching aids	Small opportunistic survey of opinions of public with respect to consent	All respondents strongly in favour of taking part in clinical teaching, no matter what the setting, with the exception of sexually transmitted diseases clinic.	Privacy and embarrassment may be issues when seeking to recruit patients as learning 'aids'
Greenfield, S et al	Community Voices: Views on the Training of Future Doctors in Birmingham	2001	Surveying potential service users about what should be taught	Qualitative research study. Data collected via focus groups.	Three main themes emerged: group's perception of the 'differences' in beliefs and behaviours of their individual community; identification of characteristics of a culturally sensitive doctor; recommendations for changes in medical training.	Whilst there were many similarities between different cultural and ethnic groups in terms of general issues, it was apparent that many differences may exist within a broad category such as 'health beliefs' which may be specific to individuals or groups.
Hanson,B. and Mitchell , D.	Involving Mental Health Service Users in the Classroom: A Course of Preparation	2001	Preparing service users to be educators	Describes and discusses a five day course aimed at training service users to be educators	The course evaluated positively. The preparation provided skills and confidence which enabled the users to develop and widen their teaching experience.	Individual and institutional blocks need to be overcome if users are to participate in nurse education. Power imbalance is an issue.
Harrison, C. and Beresford, P.	Using Users	1994	Consulting user groups regarding all aspects of social work training	Description of a consultation workshop	Several key points emerged with respect to service user involvement which indicated true collaboration and partnership and a rejection of tokenism.	The consensus of the conference was that everyone – educators, service users and trainers would gain from more user involvement in community care training.
Hutchings, D.	Partnership in Education: An Example of Client and Educator Collaboration.	1999	Service user as teacher	Narrative on one user's participation in an in-service training session.	User's session was well attended and well received	After session, subtle shift in power to closer to partnership model.
Ingham, M.	How Patients Can Contribute to Nurses' Education	2001	Creating a reference group of service users to inform education curriculum and content.	Description/commentary	The reference group addressed the process of involvement and identified ground rules for participation. These covered preparation, remuneration and support.	Members of the core development team found the presence of patients challenging initially but working collaboratively has enhanced their network of contacts.
Iskander, R.	Listen and Learn	1999	Creating a reference group of service users/carers to	Opinion piece	Attempts at user consultation by NHS	NHS has much to learn from the model of lay

			inform education curriculum and content.		workers leaves a lot to be desired and much can be learnt from accessing established consumer groups	assessment used by local authorities.
Klein, S.	The Effects of the Participation of Patients with Cancer in Teaching Communication Skills to Medical Undergraduates	1999	Users as teachers and assessors	Prospective randomised controlled study	Marked differences found between experimental group of students and control group with respect to: listening to patient, building up trust, patient choice, importance of communication and empathic understanding.	Because interview performance was assessed with patients who had cancer, it is not known to what extent the interview skills could be generalised to patients with other diagnoses.
Masters, H. et al	Involving Mental Health Service Users and Carers in Curriculum Development: Moving Beyond 'Classroom' Involvement	2002	Consulting with existing user groups for advice, teaching resources/personnel	Evaluation of the process	Project members found a change in power, status and working relationships and the users learnt new skills, increased self confidence and felt empowered. Concerns included the dissonance between idealism and reality.	User involvement in professional education requires constant energy and commitment – recommends appointment of project development worker to be essential to successful implementation.
Mansfield, E. et al	Comparison of Psychiatric-Mental Health Nursing Education Objectives: Consumers, Educators, and Practitioners	1982	Surveying the views of service users about what should be taught	Data collected from consumers, educators and practitioners via a 'card sort' indicating priorities	Top priorities of practitioners were therapeutically orientated whereas priorities of consumers were more humanistically orientated.	
Mayo-Smith, M. et al	Patient Participants in a Physical Diagnosis Course: A Study of Motivations and Experiences	1992	Users as teaching 'aids'	Data collected via structured interviews with patients who have been assigned to medical students over a seven week period.	Participants were generally positive. Most common reasons for getting involved were altruistic.	Found that patients valued it as a learning experience and contend that the experience of participation would be enhance if the learning component was enhanced.
Medio, F. and Morewitz, S.	Four Approaches to Using Patients to Teach and Evaluate Clinical Skills of Residents, Interns, and Students.	1992	Users as teaching 'aids'	Discussion paper	Discusses four traditional approaches to involving patients in medical training: bedside teaching rounds, round-table seminars, standardized patients, and the objective structured clinical examination.	Whilst these traditional approaches are seen as passive involvement, it is contended that the role can be more active.
Reynolds, J. and Read, J.	Opening Minds: User Involvement in the Production of Learning Materials on Mental Health	1999	Service users producing learning materials	Description/commentary	Highlights problems of power imbalances, potential tokenism and polarisation of priorities between users	The manner in which the curriculum writing team made a decision with the service user being present

	and Distress				(the emphasis on personal experience) and professionals (the emphasis on academic 'balance').	mirrored his experience with the mental health services and his subsequent feelings about this reflected this.
Rowley, D.	Tapping into Experience	1995	Users as teachers and assessors	Commentary on a pilot project aimed at involving users in social work training	Overall a positive experience-broke down barriers, promoted equality, students gained a user perspective. However remuneration became a contentious issue.	Service users participated in professional training by becoming course participants themselves.
Rudman, J.	User Involvement in the Nursing Curriculum: Seeking Users' Views	1996	Surveying the views of service users about what should be taught	Qualitative research study	Users want nurses to have an eclectic knowledge base that respects individual differences and the user's experience. The users' emphasis is on interpersonal skills and <i>caring</i> rather than rational knowledge.	Incorporating the views of users into mental health nursing curriculum may provide 'necessary balance' with the contemporary 'scientific' approach.
Sawley, L.	Consumer Groups: Shaping Education and Developing Practice	2002	Creating a reference group of service users/carers to inform educational curriculum and content	Description/Commentary	Comments are made re the process of consulting the groups. Outcomes: changes have been made to the educational content, practice has developed in the trusts involved, effective networking has taken place.	Facilitators anxious that forum was not used for airing complaints about specific care. Included this in ground rules and had manager present to deflect any such complaint to outside the meeting.
Soliman, A. and Butterworth, M.	Why Carers Need to Educate Professionals	1998	Carers as teachers	Description/commentary	Involvement has ranged from carer controlled content to academic controlled. Carer benefits: feeling of value and importance. Practitioner benefit: understanding carer perspective – can appreciate this more outside of ward environment.	Involvement can 'snowball' from small beginnings
Spencer, J. et al	Patient-Oriented Learning: A Review of the Role of the Patient in the Education of Medical Students	2000	Users as teaching 'aids'	Discussion paper	Whilst agreeing with the consensus that user involvement is beneficial they propose the use of a framework to stimulate this which comprises the headings: <i>Who? How? What? Where?</i>	Contact with real, as opposed to simulated, patients plays a crucial and valuable role in the training and education of doctors, but is an under-researched area.

Stacy, R. and Spencer, J.	Patients as Teachers: A Qualitative Study of Patients' Views on Their Role in a Community-Based Undergraduate Project.	1999	Users as teaching 'aids'	Qualitative study incorporating semi-structured interviews with 'patient partners'	Patients saw themselves in active roles as teachers, i.e. as experts in their own medical condition and facilitators of the development of the students' professional skills and attitudes. Patients felt they had benefited from participation e.g. talking about their problems, learning more about themselves and satisfaction from helping.	Researchers caution that despite these positive findings it is important to ask to what extent using patients as teachers in this sort of undergraduate project exploits people in the community.
Turner, P. et al	Listening to and Learning from the Family Carer's Story: An Innovative Approach in Interprofessional Education	2000	Carers as teachers	Qualitative study (observation and semi-structured interviews with multi-disciplinary students and carer participants	Students responded positively to carer involvement – they claimed it would significantly influence their professional behaviour. Carers also reported benefits and found the experience cathartic and therapeutic.	Preparation and debriefing were found to be of importance.
Twinn, S.	Creating Reality or Contributing to Confusion? An Exploratory Study of Client Participation in Student Learning	1995	Users as learning 'aids'	Case study	Despite clients' willingness and commitment to participate in student learning, factors need to be considered: selection of clients, detailed briefing of students and clients, careful monitoring of practice situation, preparation of practitioners.	Since research suggests clients have a particularly important role to play in assessing the personal attributes and attitudes of students, it is essential that their opinions are valued and taken into account.
Ubel, P. and Silver-Isenstadt, A.	Are Patients Willing to Participate in Medical Education?	2000	Users as learning 'aids'	Structured interviews with convenience sample of 100 patients.	Found that patients appear willing to act as a learning 'aid' to medical students when the procedure is fairly minor (e.g. take blood pressure) but would be reluctant to consent to take part if the procedure was more complex (e.g. a spinal tap).	Argue that many medical schools are unwilling to fully utilise patients as learning aids due to fear of refusal. Claims this study shows that this is largely unfounded.
Wykurz, G.	Patients in Medical Education: From Passive Participants to Active Partners	1999	Users as learning 'aids'	Commentary	Patients have been traditionally been assigned a passive role in medical education. Argues that the trend towards a more active participation benefits	The challenge for medical faculties will be whether they are prepared to extend the involvement of patients to collaborate in the design, implementation and

					everyone.	evaluation of the curricula.
Wood, J. and Wilson-Barnett, J.	The Influence of User-Involvement on the Learning of Mental Health Nursing Students	1999	Users as teachers and assessors	Comparative research study using a triangulation of methods	Students who were given an experience of user involvement in the classroom work differed from those in the same cohort who had not been exposed to as much user input. They were less likely to rely on the use of professional terminology and jargon, more able to empathise with clients' distressing experiences, less likely to use defensive 'distancing' and more likely to take an individualised approach to assessment and intervention.	There are a number of organisational and attitudinal barriers that need to be addressed if nurses and users are to move towards collaborative working.

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