

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

Angela Morgan
Centre for Learning and Enhancement, University of Teesside

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

Table 1 Literature Search Terms

Group 1 Professions involved in CETL4HealthNE	Group 2 Area of involvement	Group 3 People	Group 4 Other considerations – description of involvement
Medicine Dentistry Speech and language therapy Pharmacy Nursing Occupational therapy Physiotherapy Physical therapy Foundation degree Healthcare practice foundation degree Healthcare science foundation degree Complementary therapy foundation degree Allied health professions AHP Health care Healthcare professions Health professions Midwifery	2a Education Training Teaching Learning Curriculum Curriculum design Curriculum development Curriculum delivery Curriculum assessment Curriculum planning Curriculum implementation Assessment Student recruitment Course Course design Course development Course delivery Course assessment Coursework Module Service development 2b Medical education Medical training Nurse education Nurse training Healthcare education Healthcare training Dentistry education Dentistry training	Patient Client Service user Volunteer patient Patient instructor Consumer User Carer Relative Family Old people/ elderly/ aged Young people/ children/ youth Public Lay	Involvement Collaboration Contribution Joint venture Partner Partnership Participation Patient-centred Strategy Engagement Family-centred Professional development Consultation Advocacy Opinion

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	Speech and language therapy education Speech and language therapy training Pharmacy education Pharmacy training Occupational therapy education Occupational therapy training Physiotherapy education Physiotherapy training Complementary therapy education Complementary therapy training Allied health professions training Allied health professions education AHP education AHP training Midwifery education Midwifery training		
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Note: Groups were combined as follows:
1 and 2a and 3 and 4; 2b and 3 and 4; 1 and 2a and 3; 2b and 3; 2b and 3 and 4

Table 2

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

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

Table 3 Curriculum Development

Study ID No	Authors	Programme / Professional Group	Model / Approach / Strategy	Strategy Evaluation	Findings
	No Evaluation				
1	Alahlahi & Burge (2005)	UG medical education (psoriasis content)	Delphi study involving patients and professionals to help determine content	None	<ul style="list-style-type: none"> Patients placed greater emphasis on psychosocial aspects of the condition, financial burden and complementary therapies than professionals did
2	Calman (2006)	Pre-registration nursing	Study to ascertain patients' perceptions of a competent nurse and to explore their willingness to be involved in assessment of students	None	<ul style="list-style-type: none"> Being friendly, kind, having human skills and going the extra mile were seen as added extras Most felt that the reality of assessing performance of nurses would be difficult, particularly if based on one incidence
3	Curle & Mitchell (2004)	Doctorate in Clinical Psychology	Service user reference group set up to inform the curriculum	None	<ul style="list-style-type: none"> Led to enhanced user involvement and programme changes Qualities of a good and bad clinical psychologist generated
4	Forrest et al (2000)	Pre-registration nursing (mental health)	Focus groups used to elicit mental health service users views about the attributes of a mental health nurse	None	<ul style="list-style-type: none"> Being able to function as a friendly human being was seen as key Emphasis should be placed on learning with service users
5	Greenfield et al (2001)	UG medical education	Lay and professional representatives from 10	None	<ul style="list-style-type: none"> Recommendations included recruiting more students from

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			established community groups representing a range of ethnic minorities were consulted in discussion groups		ethnic minority groups, students learning basic greetings in different languages and cultural awareness sessions being delivered by people from the Black community
6	Jordan et al (2000)	Pre-registration nursing (mental health)	Service users (and lecturers and students) were interviewed regarding the bioscience aspect of the curriculum	None	<ul style="list-style-type: none"> • Students and lecturers placed minimal value on bioscience content • Service users identified that nurses lacked knowledge of pharmacology and would like the curriculum to include non pharmacological interventions
7	Flanagan (1999)	CPD cancer nursing course (Specialist practitioner qualification)	Involvement of carers and clients (with cancer) in the curriculum design group	None	<ul style="list-style-type: none"> • Users and carers suggested that the educational process must promote not stifle the affective elements of care • Better preparation was advised as was the avoidance of jargon which promotes professional exclusivity
8	Rudman (1996)	Pre-registration mental health nursing	Focus groups held with two service user groups to elicit views on curriculum and qualities of a mental health nurse	None	<ul style="list-style-type: none"> • Users required professionals with an eclectic knowledge base tailored to individual needs and good interpersonal skills
9	Sawley (2002)	Children's nursing courses	A consumer group was set up to inform curriculum development	None	<ul style="list-style-type: none"> • The reference group led to changes to educational content of programmes and practice development

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10	Whittaker & Taylor (2004)	Module on parenting skills	Parents and professionals were asked their views on local parenting support services to inform a parenting module	None	<ul style="list-style-type: none"> • General dissonance was noted between practitioners and parents views • Sound interpersonal skills and inclusion of parents in decision making were seen as crucial by parents
	Level 1				
11	Masters et al (2002)	Pre-registration Diploma in Nursing (Mental Health)	Strategy development group collected data to inform a service user involvement strategy for the curriculum	Survey of participants including users, carers and staff (n=17)	<ul style="list-style-type: none"> • Issues of representation and representativeness were a concern • Involvement led to personal development e.g. enhanced skills and confidence and changes in the curriculum philosophy

Table 4 Curriculum Delivery

Study ID No	Authors	Programme / Professional Group	Model / Approach / Strategy	Strategy Evaluation (n=)	Key Findings
	Level 1				
12	Brown & Macintosh (2006)	CPD module on heart disease prevention in primary care (nursing focused)	Involvement module steering group and in e learning materials development including video stories	Qualitative study with patients (n=27) and students (n=10)	<ul style="list-style-type: none"> • Patients found process rewarding and enjoyable • Students reported that the videos heightened interest and motivation to learn • Assessors noted that the patient's perspective was well evidenced in the module assignment
13	Butterworth & Livingston (1999)	UG medical education	Carers of dementia sufferers, as part of a formal lecturer programme, talked with medical students	Informal evaluation (numbers not stated)	<ul style="list-style-type: none"> • Students rated sessions highly • Carers felt that their caring had meaning and value and they wished to enhance the knowledge and practice of the doctors of tomorrow
14	Coleman & Murray (2002)	UG medical education (GP/ community attachment)	Medical students examine and question patients in their own home or surgery	Qualitative interviews with patients (n=15)	<ul style="list-style-type: none"> • Incentives for involvement were altruism and personal gain • Embarrassment and anxiety and concern about full access to records possibly prevented involvement
15	Cooper & Spencer-	UG medical,	Service users co-	Analysis of	<ul style="list-style-type: none"> • Students and facilitators found the

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	Dawe (2006)	nursing, social work, OT, physiotherapy programmes	facilitate inter professional team working workshops	students' reflection (n=63), a focus group with IPE facilitators (n=7) and in-depth interviews service users (n=10)	<p>experience rewarding</p> <ul style="list-style-type: none"> • Students felt it enhanced their understanding of a patient-centred perspective • Service users felt well prepared and enjoyed contributing to better relationships between professional groups
16	Costello & Horne (2001)	Pre-registration nursing (adult branch)	Involvement of 3 patients in a classroom session facilitated by a lecturer	Basic end of session evaluation (n=67) and discussion with patients (n=3)	<ul style="list-style-type: none"> • Students felt that it helped them gain an understanding of the patient's perspective although some felt embarrassed • Patients found the process cathartic
17	Frisby (2001)	Pre-registration nursing (mental health)	Involvement of users in classroom based client review using student role plays	Informal feedback (numbers not stated)	<ul style="list-style-type: none"> • Users reported enhanced feelings of empowerment • Very little resistance noted from tutors • Involvement promotes learning about users' perspectives
18	Ikkos (2003 & 2005)	Psychiatry training for qualified doctors	Involvement of patients from user groups in a basic clinical interviewing skills workshop	Informal evaluation 34 doctors (n=34 in 2003 and 57 in 2006)	<ul style="list-style-type: none"> • Sessions were rated highly and facilitated empathy and an appreciation of users role in decision making • The need for balanced expression of opinion and viewing the situation as a mutual learning opportunity was emphasised

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19	Jackson et al (2003)	Accelerated UG medical education (Inequalities in Health Module)	Students interview patients who live in socially and economically deprived areas in their home and staff from 3 services involved in their care	Qualitative study with patients / carers (n=18)	<ul style="list-style-type: none"> • Half of the patients were apprehensive and most were positive about being involved • All were willing to take part again • Being listened to was seen as a positive benefit • Involvement was seen as a way of improving the health service
20	Jones (2006)	Advanced practice clinical examination programme (nurses)	Service users acted as 'patients' in history taking and physical examination skills delivery	Qualitative interviews with service users (n=7)	<ul style="list-style-type: none"> • Users found the process empowering and it increased their knowledge about their condition • They felt a sense of belonging and felt that their contributions were valued
21	Kelly & Wykurz	UG Medical Education(1 st and 2 nd year)	Students made 5 visits to a patient partner and received formative feedback on communication and comments on summative work	Evaluation meetings involving 136 patient partners and 136 students.	<ul style="list-style-type: none"> • Students reported enhanced communication skills • Patient partners reported increased confidence • The community tutors were positive
22	Khoo et al (2004)	Postgraduate Diploma / MA in mental health	Involvement of service users in classroom seminars	Survey of students (n=26) and qualitative interviews students (n=10)	<ul style="list-style-type: none"> • Students rated the user contributions as good or excellent • Process fostered a desire to change services • Representativeness was questioned

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23	McAndrew & Samociuk (2003)	Pre-registration nursing (mental health)	Service user involvement in classroom based reflection sessions	Survey of students (n=7) and service users (n=5) at the start of the project	<ul style="list-style-type: none"> • Users felt that they were in the dominant position as they could offer real life experience • Students felt that through the process there would be sharing and growing for all concerned
24	Maughan et al (2001)	UG medical education	Students meet a patient with cancer regularly over a 6 month period. Interactions are recorded in a diary and assessed	Informal evaluation (n=144)	<ul style="list-style-type: none"> • Students reported increased confidence talking to patients with serious illnesses and gained insight into multi-disciplinary working and problems patients faced • Found it emotionally challenging when patient dies and problematic in relation to the assessment
25	Ottewill et al (2006)	Pre-registration physiotherapy	Two patients who had experienced a stroke told their stories in the classroom	Qualitative interviews with students (n=6)	<ul style="list-style-type: none"> • The impact on learning was considerable • The unconventionality of the session raised anxieties • Students assumed a more passive role than usual
26	Read & Spall (2005)	Post-registration palliative care diploma (nurses)	Stories and biographies used to explore palliative care	Informal evaluation (n=6)	<ul style="list-style-type: none"> • Session gave an insight into users and carers feelings and enhanced their understanding of the meaning of illness
27	Rush & Barker (2006)	Pre-registration Diploma in Nursing (Mental Health)	Involvement of service users in 3 EBL sessions	Survey of students (n=26)	<ul style="list-style-type: none"> • All students reported positive impact on their learning and service user involvement improved the EBL trigger

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28	Shah et al (2005)	UG pharmacy education (first year)	Patient volunteers lead a tutorial, were interviewed as part of history taking and communication skills development and gave formative feedback on performance	Qualitative interviews with patients (n=14)	<p>Patients reported</p> <ul style="list-style-type: none"> • altruistic reasons for involvement • enhanced knowledge about their illnesses and medication • that they were more questioning of health care professionals • enhanced self-esteem and confidence and relief from social isolation
29	Simons et al (2006)	Mental health nursing programmes	Appointment of service user to an academic post	Anecdotal (full evaluation reported after cut off date)	<ul style="list-style-type: none"> • The post facilitated user participation in education being part of everyday activities of the academic team and the post holder was able to support, appraise and review the contributions of other users
30	Stacy & Spencer (1999)	UG Medical Education	Students visit a patient regularly over a 6 month period	Qualitative interviews with patients (n=20)	<ul style="list-style-type: none"> • Patients saw themselves as experts in their own condition • They benefited from having someone to talk to and for some it relieved loneliness • It facilitated insight into their own condition • Some gained satisfaction from helping students in their education
31	Turner et al (2000)	Pre-registration programmes including medical, nursing, social work	Students interview carers of people with a terminal illness (or are	Qualitative interviews with 12 carers (n=12) and focus groups with	<ul style="list-style-type: none"> • Students felt privileged to hear the stories and behaved sensitively when carers became upset • Carers found it cathartic but would

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		and rehabilitation therapy students	recently bereaved) in inter-professional groups in a workshop	students (n=40). Participant observation of session	have liked more specific guidance and time to tell their stories
32	Whitehead & Harding (2006)	Post-registration module (gastrointestinal and liver)	Facilitation of a conference morning including service users and clinicians	None	<ul style="list-style-type: none"> States that the conference was successful
33	Walters et al (2003)	UG medical education (year 4 psychiatry attachment)	Patients with mental disorders are interviewed by students in the GP surgery	Survey of patients (n=115) and qualitative interviews with patients (n=20), GP tutors (n=12) and students (n=14)	<ul style="list-style-type: none"> Personal benefits for patients included enhanced self-esteem, development of a coherent narrative and new insights into their health. The students were viewed as non-judgemental and enthusiastic. No distressing consequences were reported by students
	Level 2				
34	Eagles et al (2001)	UG medical education (4 th year psychiatry block)	Students were taught history taking skills by either a real patient (n=54), a simulated patient (n=46) or by observing a video tape of an interview (n=56)	Non-randomised comparison between the three groups. Outcomes measured included knowledge and attitudes	<ul style="list-style-type: none"> No significant differences found between the groups on knowledge and attitudes There was a slightly higher satisfaction score for the simulated patient

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35	Haq et al (2006)	UG medical education (year 3)	Involvement of 4 Patient Partners (PP's) with back pain in 2 clinically based teaching sessions	Non-randomised comparison (n=60 PP group and n=54 in control group) and qualitative focus groups with PP's (n not given)	<ul style="list-style-type: none"> • PP's took part for altruistic reasons and benefited from increased knowledge of their condition and increased confidence • There were no differences between OSCE scores between the two groups
36	Raj et al (2006)	UG medical education	Involvement of patient educators (PE) with arthritis to deliver the rheumatology curriculum	RCT with an experimental group (PE) (n=25) and a control group (n=25). Qualitative interviews with PE's (n=6) and students (n=6).	<ul style="list-style-type: none"> • PE's achieved acceptable scores on student evaluation of teaching form but doctor led teaching scored higher • No significant differences in OSCE scores between the two groups • PE's enjoyed the training and reported an increase in self-worth and confidence and being able to use their illness in a positive way
37	Wood & Wilson-Barnett (1999)	Pre-registration nursing (mental health branch)	Involvement of service users in classroom activities	Non randomised comparison (cross over) with 15 students in each group using a user centred measurement tool	<ul style="list-style-type: none"> • Service user input led to less use of professional jargon, more empathy and less distancing • Students exposed to input more likely to take an individualised approach to assessment and intervention • Students expressed concern about potential discomfort and representativeness
	Level 3				

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38	Klein (1999)	UG medical education (3 rd year)	Involvement of either patients with cancer (experimental group n=123) or patients with other diagnoses (control group n=126) in an interviewing skills training programme	RCT with measurement at the end of the sessions and at a 2 year follow up. An interview rating instrument was also used to rate a real life interview with a patient with cancer	<ul style="list-style-type: none"> • Students taught interviewing skills by patients with cancer demonstrated better communication skills than those taught by patients with other diagnoses
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Table 5 Assessment of students (main focus)

Study ID No	Authors	Programme / Professional Group	Model / Approach / Strategy	Strategy Evaluation (n=)	Findings
	Level 1				
39	Bailey (2005)	MA Community Mental Health	Users were asked their perceptions of summative work and gave feedback	Action research involving discussion with users and a focus group with programme participants (n=9)	<ul style="list-style-type: none"> • Users reported enhanced confidence and knowledge about services offered and new friendships • Students reported mixed views on the helpfulness of the feedback and generally wouldn't make any major changes to their practice based on it

Table 6 Programme Evaluation

Study ID No	Authors	Programme / Professional Group	Model / Approach / Strategy	Strategy Evaluation (n=)	Findings
40	Forrest et al (2004) Part I (methodology) and II (outcomes)	CPD course on Psycho-social interventions (PSI)	Stakeholder conference and meetings with users and carers to generate programme evaluation outcomes	Involvement of service users in evaluation not evaluated	<ul style="list-style-type: none"> • Development of a good working relationship was seen as important • Only one service user was aware of what PSI was and none were aware of receiving it. The qualities of the worker were seen as more important than the intervention

Table 7 Integrated Strategy

Study ID No	Authors	Programme / Professional Group	Model / Approach / Strategy	Strategy Evaluation (n=)	Findings
	Level 4b				
41	Barnes et al 2000 & 2006	MA Community Mental Health	Service user involvement in programme commissioning, selection of staff, programme board and curriculum committee, programme delivery and evaluation	Formal external evaluation using a variety of methods to look at changes in knowledge, attitudes, skills and user generated practice outcomes	<ul style="list-style-type: none"> • Programme participants agreed with the user centred values of the programme. • Some user contributions were perceived as too antagonistic by participants • All could describe how their practice had developed to enhance user involvement • A higher proportion of programme participants' users reported good user-centred assessment and care planning compared to a comparison group