The Health Foundation

Inspiring Improvement

Report:

Can patients be teachers?

Involving patients and service users in healthcare professionals' education

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Contents

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Preface

Following a workshop on self care, discussions began between the Health Foundation and a group of academics involved and interested in developing the active role of patients in medical education. This report stemmed from those discussions.

It was felt that a description of the 'state of the art' of both practice and scholarship in the UK would be a useful starting point.

The Health Foundation's original interest was in medical education, but the inquiry was broadened to look at involvement in education across all health and social care professional groups, as well as international activity.

It builds on the work of the Patients as Educators Research Collaborative (PERC), an international and interdisciplinary group of educators and researchers formed in Vancouver, Canada, in 2008, of which all the authors are members. The academics who originally discussed the idea have been the advisory group to the project and commented on the final report.

John Spencer
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Executive summary

1.1   This report is based on: a literature review, a series of case studies of mostly successful initiatives identified in the literature and followed up by telephone interviews, and a web-based survey of UK medical and dental schools.

1.2   Involvement of people who are patients, carers and service users (patient/user) is widespread and characterised by great diversity. This involvement is well established in certain sectors of health and social care professional education in the UK, notably social care and non-psychiatric mental health. In other areas it is patchy, particularly in medical education, and especially in postgraduate and continuing professional development, where comprehensive involvement at all levels is uncommon. Nonetheless, most reported innovations appear to be single educational experiences for a specific group of learners, and are often isolated examples within the broader curriculum.

1.3   With some notable exceptions, highlighted in the case studies, generally patient/user involvement in health professional education is low on the agenda of influential leaders in health professional education, either at the institutional or national level. There are intentions to develop involvement work but this tends to be afforded relatively low priority.

1.4   There is strong evidence that patient/user involvement has short-term benefits for all involved, including learners, educators, institutions and patient/users, across a wide range of domains, such as knowledge, skills, attitudes, behaviours. Longer term, there has been little evaluation to discover whether patient/user involvement has an effect on the behaviour or practice of health professionals or on health outcomes.

1.5   Innovations require a champion, institutional buy-in, support, adequate infrastructure and funding. Policies and processes need to be in place to address issues such as recruitment, remuneration, ethical issues, training and on-going support. Significant cultural change may be required within institutions as patient/user involvement becomes embedded.

1.6   Good quality research is required to further develop the evidence base. This needs to go beyond the common descriptive studies that describe 'what we did' with a fairly low level and short-term evaluation. There is a need for more clarification research that addresses longer term issues, including effects on behaviour of health professionals and health outcomes, factors influencing sustainability. This research needs to identify best practice – such as 'why does this work here, and not there?' Research of this kind should be a priority and it will require a programme of funding.

1.7   There is a need for a central repository of good practice. This includes developing a database of innovations and materials that can facilitate knowledge transfer to benefit all stakeholders. There is also a need to facilitate development of involvement, for example, through conferences and workshops.

1.8   We recommend holding a series of meetings that bring together leaders and thinkers from academic institutions, professional bodies, the healthcare system, the lay community and other stakeholders interested in health professional education to address the issues raised in this report.

Acknowledgements

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1 Introduction

Interacting with people who experience health conditions or receive health and social care, or both, should be central to the education and training of the health professionals who will treat them.

In professions such as nursing, with training historically largely workplace based, patients and patient care have featured prominently. In medicine, this has not always been the case. In some European countries the main approach in medical schools is still to teach medicine mostly in the lecture hall and laboratory, with relatively little and late patient contact.

Nonetheless, Sir William Osler's famous quote will chime with the vast majority of clinical educators, their learners and, intuitively, patients alike:

'for the junior student in medicine and surgery, it is a safe rule to have no teaching without a patient for a text, and the best teaching is that taught by the patient himself.'

(Osler, 1904)

Whatever the context or discipline, the patient's role, while recognised as crucial, has still been largely passive. At worst, in the medical context, and somewhat stereotypically, involvement has been something forced on a hospital patient unable to say no to a consultant and his students around the foot of the bed. At best, the patient, though treated with courtesy, has usually been little more than a medium through which the clinical teacher taught.

Since the 1980s, developing through the 1990s, actively involving people in healthcare has become an important strand of UK government policy. Now, in the patient-led NHS, it is one of the key underlying elements of reform and modernisation.

It is a requirement that 'patient and public involvement should be part of everyday practice in the NHS and must lead to action for improvement.' (Department of Health, 2005). This inevitably also includes involvement in training and education for health professionals.

There have been many innovations in how patients and carers are involved in educating health professionals, some stretching back several decades. In medicine they have tended to be isolated examples of good practice, often dependent on the efforts of individual champions.

In other areas, notably mental health education and training (non-psychiatric) and social care education, user involvement is embedded at many levels in curricula (Tew et al., 2004; Levin, 2004). This goes beyond rhetoric. For example, the General Social Care Council requires that user involvement is in the social care curricula they regulate (GSCC, 2007).

Significant literature has also emerged and several reviews have been published (Spencer et al., 2000; Repper & Breeze, 2007; Jha et al., 2009; Morgan & Jones, 2009; Towle et al., 2010; Jha et al., 2010), exploring relevant aspects and issues, both theoretical and practical.

There is a broader context, namely social accountability. This is defined by the World Health Organization as:

'the obligation [in this instance, of medical schools] to direct their education, research and service activities towards addressing the priority health concerns of the community, region, and/or nation they have the mandate to serve'.

(Boelen & Heck, 1995; Boelen, 1996)

Social accountability has evolved as a major contemporary discourse, embracing notions such as: social responsibility (of health professionals) (Woollard, 2006); the social contract (between professions and society); and social responsiveness (of the institutions training the professionals). Public engagement is another contemporary theme and driver of policy, not least in higher education.

The National Coordinating Centre for Public Engagement (NCCPE) was established in the UK in 2008 as part of the Beacons for Public Engagement Project. The aim is to create culture change across the higher education sector. Six beacon sites, university-based collaborative centres working to support, recognise, reward and build capacity for public engagement, have been established around the UK.

Public engagement has been described by the NCCPE as follows:

'Public engagement brings research and higher education institutions together with the public. It generates mutual benefit – with all parties learning from each other through sharing knowledge, expertise and skills. Done well, it builds

trust, understanding and collaboration, and increases the institution's relevance to, and impact on, civil society.'

(NCCPE, 2009)

These developments have occurred alongside changes in public expectations, resulting from declining deference towards professionals and the rise of consumerism, a move from paternalism towards partnership, along with greater understanding of what healthcare can achieve.

People increasingly expect to have their ideas and concerns addressed, be informed about their condition and briefed about treatment risks and benefits. They expect to be involved in decisions about their care and educated and supported in managing their own problems.

Besides changes in patients' expectations, there is now a greater appreciation about the environmental, social and psychological determinants and consequences of ill health, and about healthcare treatments. There is a need, especially in medicine, for new models to guide clinical practice. These have included the bio-psycho-social model (Engel, 1989), patient-centredness (Stewart et al., 2003), shared decision making (Coulter, 2009), and, most recently, and radically, self care (the Health Foundation, 2008). All put the patient's experience, perspective and priorities at the centre – or, in the case of 'self care', in the driving seat.

Finally, it is well recognised that carers, while making a major contribution to health and social care in the community, are generally poorly supported. They may suffer significant health problems themselves, and economic hardship, and their voice often goes unheard.

Together these circumstances present new challenges for working more effectively with patients, their carers and families. For example, supporting and enabling choice in situations of uncertainty, helping people to understand available options and the risks involved, and to appreciate restrictions on choice.

Teaching and learning about how to do these things needs input from these people. This is so that health professionals learn about, from and with people who are experts about their own lives, and so they can learn how to approach interactions as partnerships. Their interaction should be a meeting of experts that combines the experiential knowledge of the patient with the technical expertise of the professional (Tuckett et al., 1985). This challenges educators to seek the most appropriate ways of enabling learning while respecting the rights, needs and values of patients, carers and their families.

This report aims to describe the current 'state of the art' of active patient (or other user) involvement in the education of health and social care professionals, in both the literature and in practice.

It aims to highlight areas for further research and development. The medical, nursing (especially mental health nursing) and social work education health professions feature prominently in this report. This is because most of the research is drawn from these areas.

2 Methods

This report builds on work already undertaken at the University of British Columbia (UBC), Vancouver, Canada, and under the auspices of the UK Higher Education Academy Subject Centre for Medicine, Dentistry and Veterinary Medicine.

A comprehensive review of the literature, a survey of participants at an international conference (Farrell, Towle & Godolphin, 2006), and a canvass by e-mail of international networks and contacts, enabled a comprehensive database to be compiled. It comprised nearly 300 papers, from nine countries, all published in English between 1970 and mid-2009 (Towle et al., 2010). Most came from medicine (64%), nursing (15%) or social work (11%) and 9% were multi or interprofessional (see Towle & Godolphin, 2010 at: www.chd.ubc.ca/dhcc/node/67).

In 2009, a web-based survey was taken of authors of papers that described educational initiatives. It was funded by a grant from the Martha Piper Research Fund at University of British Columbia (UBC) to find out whether the documented programme was still running, whether it had grown, stayed the same or changed into something else. It aimed to explore the factors important in initiating and sustaining the programmes, or in contributing to their demise. There were 181 index papers and 59 responses were received. Of these 14 programmes had stopped, 32 had continued and nine had been replaced. The respondents to the Martha Piper survey formed the sampling frame to identify initiatives as case studies for our report. Ethical approval was obtained from respective ethics committees at Newcastle University and the University of British Columbia.

Sampling was purposive, aiming to select initiatives from different levels of the 'spectrum of involvement' (Towle et al., 2010, see description in Section 4: Classification, table 1 in Section 5: Literature review and Appendix 4). It also aimed to cover a range of disciplinary backgrounds, levels of education, geographical locations and approaches. A small number of other initiatives known to the authors through established networks were also included.

Contacts were sent a letter of consent and a reminder by email (Appendix 1). If they consented, a date was fixed for telephone interview. Interviews were carried out by two of the authors (John Spencer, Natalia Karpenko) and were tape-recorded for later reference. The schedule comprised the nine questions in the consent letter (Appendix 1). The case study text was then drafted, using the following headings:

– Description and history
– Funding and structure
– Programme evaluation
– Programme contacts
– Other initiatives and additional information
– Outputs and resources.

The draft was returned to the respondent for validation and amended accordingly. In the end, 24 case studies have been included in this report. See Section 6: Case studies.

In 2007, one of the authors (John Spencer) had received a small grant from the HEA Subject Centre for Medicine, Dentistry and Veterinary Medicine (MEDEV) to fund an inquiry into the 'state of the art' of user involvement in medical and dental education in the UK.

Two workshops were held in early 2007 (in Leeds and Warwick) and some of the grant supported a literature review (Morgan & Jones, 2009) and a survey of current activity. This was reactivated for the purposes of the current report.

A short web-based questionnaire was constructed with the help of the Subject Centre and sent to all their so-called Nominated Primary Contacts (NPCs) in UK medical and dental schools (with a covering email).

Respondents were asked to:

– rate activity in their own institution against Tew et al.'s 'Ladder of involvement' (Tew et al., 2004, see Appendix 3)
– comment on whether they had plans for further developing user involvement and what level of priority these had
– describe any challenges or problems they had encountered
– offer any further comments.

The survey was launched in January and then again in March, each with reminders.

In summary, the data that inform this report are:

– a comprehensive literature review
– a series of case studies based on telephone interviews
– a national web-based survey in the UK.

3 Terminology and language

The language we use transmits the values and beliefs we hold. Language and terminology both reflect and shape social perceptions and power relations. The language of patient involvement is confusing and controversial. The use of the word patient itself is emotive.

The term 'patient' is associated in many people's minds with passivity, the sick role, and disempowerment. As such it sits oddly with recent rhetoric about the importance of patient empowerment, the expert patient (Department of Health, 2001) and the activated patient. In the UK, the term 'user' or 'service user' has increasingly replaced 'patient' in relation to involvement in health and social care service delivery, research or education.

These are not terms found in North America, where 'user' is often associated with illicit drug use. In some health professions, client is the preferred term and the preferred relationship. But there are also consumers, mental consumers, people with… [a condition, disability], such as 'people with HIV/AIDS', survivors, activists, people in recovery, experts by experience and so on. Yet even people with the same condition cannot agree on what they would like to be called: the meaning of these words makes explicit a person's attitude towards their illness, and this can change over time as the course of their disease changes (Speed, 2006). The words people use to describe themselves reflect their relationship with their illness or disability and can therefore have personal and emotional significance.

There is a political as well as a personal dimension to the language. McLaughlin (2009) traced the development of terms that are used to identify the relationship between those who provide social work services in the UK and those who receive them.

Since the late 1970s, the changing terms of 'client', 'customer', 'consumer', 'service user' and 'expert by experience' have been linked to changes in government policy. Policy has shaped the identity of the receiver of services and their relationship with service providers. Though service user is currently in vogue, its shortcomings are now being articulated, especially in the fields of social work and mental health. For example, it defines a person by a single narrow aspect of their life (using a specific service), it neglects those who do not or cannot access services, and it does not devolve power or respect to the people who use services (Cowden & Singh, 2007, Lloyd, 2008). To quote McKeown et al.:

'[service user] can at various junctures be implicitly or explicitly pejorative, demeaning and stigmatizing.'

(McKeown et al., 2010)

Further complicating matters, not all 'patients' or 'service users' involved in health professional education are ill or currently receiving care. There are many healthy people who have perspectives or experiences valuable to health professional learning. These include seniors, care givers and family members of people with chronic illnesses or disability, parents of normal children, people from specific ethnic groups, refugees, people who are marginalised or disadvantaged (for example, the homeless or recent immigrants). The term 'lay' may be more inclusive but it defines people in terms of who or what they are not (a professional). It implies a lack of expertise, and in our experience is universally disliked even by people who cannot agree on any other term. There are also 'citizens', 'community members' and 'the public'.

All these words, and more, have been used to describe those involved in educating health professionals, who are not academics or health professionals themselves. Even here the boundaries are blurred. There are many health professionals who become patients and tell of their experiences, and there are service users who have been brought into the academic institution and given a title such as 'consumer academic' (Happell & Roper, 2002).

The term 'carer', usually taken to mean a person, often a family member, who looks after someone else in an unpaid capacity (although they may be beneficiaries of welfare payments), is less contentious. Nonetheless, in North America the more usual term is 'caregiver'.

Does it matter what terms we use? For some people it brings out strong emotions and becomes a barrier to communication. As McLaughlin (2009) points out, whichever discourse we wish to use identifies a power dimension and hierarchy of control.

The language we use labels individuals in different ways and in so doing acts as both a signifier and an external control. Whichever word we use is descriptive not of a person but of a relationship. Each of these words carries different meaning and none is acceptable to everyone as an alternative to 'patient'.

Interestingly, some studies have reported surveys of the views of people under active (psychiatric) care with mental health problems about appropriate terms to describe them. Preferences varied according to which health professional the person was interacting with, but for the great majority the preferred term was 'patient'. The authors of the most recent such study were moved to conclude, 'National and local mental health services should adopt evidence-based terminology in referring to "patient" or, in some groups, "patient or client" in preference to "service user."' (Simmons et al., 2010).

We need to accept and agree that there is not, and likely never will be, one universal or acceptable term. Out of the great variety of words in current use, three seem to be used most frequently.

- In nurse and medical education 'patient' is still the most widely used and understood term.
- In mental health and social work 'service user' is the commonest term in the UK (though there are signs this may be changing).
- In other health professions (where there may be a commercial relationship) and other parts of the world 'client' is the current equivalent.

In this report we mostly use the term 'patient' or 'patient/user', although, particularly in the text of the case studies, we apply the term used by the authors of the relevant papers. We recognise that some readers may prefer other terminology.

4 Classification

Patients/users play many different roles in the education of health professionals. The degree of their involvement can be characterised along a spectrum of engagement, from minimal involvement to full partnership. In published work, rarely is the patient's role in the educational programme exactly described. This is especially true regarding the degree to which their role is explicitly identified as a teacher, and the degree to which they are actively involved in decision making about the educational programme. Several schemes have been developed to try to classify these variables, so that initiatives can be described consistently and similar initiatives can be identified and compared.

4.1 Cambridge Framework

The 'Cambridge Framework' (Spencer et al., 2000) was developed to facilitate discussion about the involvement of patients in clinical education. It is based on four sets of attributes of situations and environments where patients, students and teachers interact:

– Who: the individual background, culture and experience of each patient, their family and carers.
– How: including, patient role (passive or active), nature of encounter, length of contact, degree of supervision.
– What: the content of the education including type of problem (general versus specific) and the knowledge, skills and values to be learned.
– Where: location of interaction (for example, community, hospital ward, clinic).

The Cambridge Framework (Appendix 2) is a tool for potentially evaluating the involvement of patients in the educational process.

It could be used by curriculum planners and educators to review and monitor the degree to which patients are actively involved. The tool has not been validated.

4.2 Ladder of Involvement

Tew et al. (2004) described a 'Ladder of Involvement' in curricular development and delivery ranging from 'no involvement' to a 'full partnership'. In full partnership, patients and faculty members work together to make decisions about content and jointly deliver educational sessions. The tool was developed in the context of mental health education and training but is theoretically applicable to other educational programmes and across the educational continuum. It can be used to monitor patients' levels of involvement within individual programmes and institutions. Trent Strategic Health Authority published a set of principles for practice (Trent Strategic Health Authority, 2005) that neatly summarises the Ladder's levels:

Level 1: Little involvement

The curriculum is planned and delivered with no consultation or involvement.

'They know best. We do as we are told.'

Level 2: Emerging involvement

There is contact with local user and carer groups. They are invited to 'tell their story' and occasionally consulted in relation to planning when invited, but have no opportunity for shaping as a whole.

'This is not about people listening or service users "getting things off their chests". There are so many ways to be involved.'

Level 3: Growing involvement

Users and carers start contributing in more than one aspect of education and training, they are reimbursed, and organisations begin to plan things that will help support involvement, for example, training, mentoring.

'This is beginning to make sense.'

Level 4: Collaboration

Users and carers are contributing to key discussions and decisions and the value of this is acknowledged by all concerned. A coordinated programme of involvement and support is developing.

'I thought I could help a bit. Now I realise my contribution makes a difference.'

Level 5: Partnership

All partner groups are working together equally. All key decisions are made jointly, mutually valuing the perception and ideas of service users and carers, academics, practitioners and learners alike.

'We're all on the same side. We all want to make a difference.'

See Appendix 3 for the full 'Ladder of Involvement' framework.

4.3 'Spectrum of Involvement'

Towle et al. (2010) have proposed a taxonomy with elements of both these models based on a comprehensive review of the literature. The purpose of this classification scheme is to help to clarify the patient's role and make it easier to communicate the study of different initiatives. It can also be used to track changes over time to answer questions about how and why the role or degree of engagement changes. Their Spectrum of Involvement model identifies six main educational roles (these are not exclusive):

– paper-based or electronic case/scenario
– standardised/simulated patient
– patient shares their experience with students within faculty-directed curriculum
– patient teacher(s) involved in teaching and/or evaluating students
– patient teacher(s) as equal partner in student education, evaluation and curriculum development
– patient(s) involved at the institutional level in addition to sustained involvement as patient teacher(s) in education, evaluation and curriculum development for students.

For each of these roles they identified six attributes associated with the degree of involvement:

– degree to which patient is actively involved in the learning encounter
– duration of contact with learner
– patient autonomy during the encounter
– training for the patient
– patient involvement in planning the encounter and curriculum
– institutional commitment to patient involvement in education.

This taxonomy was refined in subsequent field testing (Towle et al., 2010, unpublished). In this version the attributes were modified to create a 'Degree of Engagement' scale that defines the degree of involvement that patients have within each role (see Appendix 4). This scheme is used as the template for classifying the case studies in this report (see table 1).

5 Literature review

5.1 Active involvement of patients in the educational process

The teaching role

The earliest examples of active patient involvement in teaching are interventions in which the patient was an instructor of clinical skills (Barrows & Abrahamson, 1964). In these programmes, now commonplace, patients teach students how to conduct physical examinations and provide feedback (Stillman et al., 1980). The patients are typically provided with training about anatomy, examination techniques and how to teach and evaluate students.

The longest lasting programmes are found in North America where many medical schools have a cadre of healthy women who teach the intimate examinations – pelvic, breast, rectal. These programmes originated in the 1960s as it became increasingly difficult for students to learn and practise these examinations in an ethically acceptable manner (Kretzschmar, 1978). They persist because no alternative method has been found that is as acceptable and effective.

Another long-lasting intervention is the 'arthritis educator' programmes in which highly trained patients teach the musculoskeletal examination (Towle et al., 2010). In some cases the expertise of patients has been used to augment the pool of clinical teachers in smaller disciplines, such as rheumatology.

A recent systematic review of studies about the involvement of patients in teaching intimate examination skills highlighted that such schemes often do not involve a health professional teacher (Jha et al., 2010).

Over the last two decades, educators have tapped into the expertise of patients to enrich the education of students in a variety of ways, providing learning experiences that could not otherwise occur and broadening out the curriculum from the biomedical model. There is a wide variety in the range of patients who have shared their experiences of living with illness or disability, although most schools only focus on one patient group.

Typically one or more patients are invited into the classroom or a small group tutorial to tell their stories and answer questions from students. Examples include people with HIV/AIDS (Vail et al., 1996; Solomon et al., 2005), cancer (Plymale et al., 1999), dementia (Skog et al., 2000) and mental illness (Coodin & Chisholm, 2001). Home or family attachment schemes permit students to interact with patients over a period of time to learn about a variety of chronic conditions in the wider community context (Stacy & Spencer, 1999; Gaver et al., 2005; Anderson et al., 2003).

Some of these initiatives specifically aim to promote positive student attitudes towards certain stigmatised groups, including people with learning disabilities or mental illness, the elderly (Westmoreland et al., 2009) and the gay community (Foreman & Quinlan, 2007).

Other programmes aim to sensitise trainees to the needs of underserved populations that are in need of more doctors such as geriatrics, or complex conditions such as childhood chronic illness. Examples include workshops run by professional actors with learning disabilities (Hall & Hollins, 1996) or teaching by parents of children with developmental disabilities or chronic illness (Hanson & Randall, 2007).

Community-based programmes include senior mentor programmes (Stewart & Alford, 2006). In these programmes students are partnered with an elderly person who is 'ageing well', or placed with people living in deprived inner city areas and workers in the agencies that provide them with services (Jackson et al., 2003; Lennox & Petersen, 1998).

In mental health and social work, programmes are designed to promote partnerships between practitioners, service users and carers. Many involve people with mental health problems. Teaching objectives include:

– enhancing partnerships between nurses and patients
– validating patient experiences
– designing therapeutic interventions congruent with patient needs
– teaching principles of equality, patient empowerment and service user involvement (Langton et al., 2003).

Repper and Breeze (2007) note that anecdotally the most common way that service users are involved in the classroom is when they are invited to tell their own story, yet there are few published accounts and no evaluations of this approach.

Some initiatives have used specific strategies to promote partnerships between patients and learners. For example, 'facilitated dialogue', a technique used to provide an arena for meaningful dialogue between two groups that are unequal in power and position.

This has been used with social work students and mental health clients to enhance student attitudes towards people with mental illness (Scheyett & Diehl, 2004). Katz et al. (2000) describe a council of elders in which medical postgraduate trainees and community elders collaborated to create a community of resources. Participants were capable of identifying novel ways to overcome health-related difficulties that might not have been apparent to either group separately.

The extent of the expertise that patients have to offer health professional education continues to expand. For example, at the University of British Columbia, two of the authors (William Godolphin and Angela Towle) have worked with patients on topics that were identified as important by the patient educators. They have worked with patients with mental health problems, arthritis, epilepsy and their caregivers, and HIV/AIDS, to develop patient-led workshops about a diverse range of topics. These topics have included:

– living with chronic disease, both day-to-day and over time
– the diversity of the illness experience
– effects on partners and families
– physical examination skills
– diagnostic challenges
– stigma and stereotyping
– peer support
– practical aids to daily living
– advice about what health professionals can do
– and information about support groups in the community.

The ongoing publication of new initiatives in the literature indicates that patient involvement in teaching continues to be explored.

See table 1 for a summary of examples of patient involvement classified by patient role(s).

Other educational roles

Although involvement in curriculum delivery is the commonest role, patients have the potential to make a major contribution to all aspects of the educational process. The most comprehensive list is provided by Tew et al. (2004). They give examples of patient involvement in:

– direct delivery of teaching and learning
– curriculum or course planning
– programme management
– recruitment and selection of students
– practice learning
– student assessment
– course evaluation
– courses as participants.

In medical education patients are mainly involved in curriculum delivery and, to a lesser extent, curriculum development and student assessment (Jha et al., 2009). Few of the other roles are currently represented. Morgan and Jones (2009) found no studies that mentioned involvement in the recruitment and selection of students and only one that focused specifically on the assessment of students. In nursing and social work a greater range of patient involvement is reported.

The review by Repper and Breeze (2007), mostly of nursing initiatives, identified the following approaches: gaining consumers' views through surveys, reference groups, conferences and invitation onto existing groups; consumer involvement in the production of learning materials; consumers as teachers and assessors.

As an illustration of the range of input into curriculum planning, service users and carers have been involved in the design and delivery of a Diploma of Higher Education in Nursing (Masters et al., 2002), the development of a new pre-registration nursing course (Ingham, 2001), the design of continuing education and higher education in cancer care nursing (Flanagan, 1999), and the production of an Open University course on mental health (Seden et al., 2005).

The impact of these initiatives is considered later.

See also table 1 for a summary of examples of patient involvement classified by patient role(s).

Stage of training

Patient involvement occurs throughout the continuum of education from undergraduate or pre-registration education, post-registration, postgraduate or specialist training, continuing professional development (CPD) and in-service training. The majority of reported initiatives occur in undergraduate courses or in the postgraduate training of mental health professionals (for example, nurses, counselling psychologists, psychiatrists).

At one end of the continuum of training, early patient or community contact in medical school frequently consists of an attachment to a patient with a chronic illness, a pregnant woman, a family or a community agency. In some cases the patient, family or community agency may be explicitly identified as a teacher or mentor. At the other end of the training continuum the role of the patient-teacher in working with multi-professional or inter-professional teams of providers is also gaining recognition. Many of these initiatives occur as part of postgraduate or in-service training and most frequently involve people with mental health problems. Patient organisations may contribute to or lead CPD activities on specialised topics, such as fetal alcohol syndrome, and there may be public members on committees that plan CPD (British Medical Association, 2008).

Table 1: Examples of initiatives for each patient role in the 'Spectrum of Involvement' (see Appendix 4)

Patient role	Examples	Selected references	Case studies
1. Patients involved in creating learning materials used by faculty (eg paper-based or electronic case or scenario; course materials; videos).	Real patient problems as basis for problem-based learning. Virtual patient cases (may involve video of patient). Use of patient narratives.	Chur-Hansen & Koopowitz, 2004 Dammers et al., 2001 Kumagai, 2008 Nicolaidis, 2002 Seden et al., 2005	Case 1 (Nicolaidis)
2. Standardised or volunteer patient in a clinical setting.	Standardised patients (SPs) widely used to teach and assess communication and clinical skills. Clinical teachers may encourage volunteer patients to teach and give feedback. Students write up patients' stories.	Ashley et al., 2009 Collins & Harden, 1999 May et al., 2009	Case 2 (Abbott)
3. Patient shares his/her experience with students within a faculty-directed curriculum.	Patients invited into the classroom to share experiences of chronic illness, disability etc. Community-based patient/family attachment programs. Senior mentor programmes.	Stacy & Spencer, 1999 Stewart & Alford, 2006 Waddell & Davidson, 2000	Case 3.1 (Hoffman) Case 3.2 (Schlank) Case 3.3 (Hollins) Case 3.4 (Waddell) Case 3.5 (Spencer) Case 3.6 (Jackson et al.)
4. Patient-teacher(s) are involved in teaching or evaluating students.	Teaching associates trained to teach and assess specific clinical skills (eg pelvic or breast exam). Parents give feedback to students on communication skills.	Gruppen et al., 1996 Raj et al., 2006 Siegel, 2007	Case 4.1 (Branch) Case 4.2 (Bell) Case 4.3 (Gecht) Case 4.4 (O'Keefe) Case 4.5 (Siegel) Case 4.6 (Theroux) Case 4.7 (Hague)

Continued...

Table 1: Examples of initiatives for each patient role in the 'Spectrum of Involvement' *continued...*

Patient role	Examples	Selected references	Case studies
5. Patient teacher(s) as equal partners in student education, evaluation and curriculum development. Patient educators involved in multiple programme areas.	Patient educators collaborate in educational decision making (eg curriculum objectives, assessment criteria).	Hanson & Randall, 2007	Case 5.1 (Hanson) Case 5.2 (Solomon) Case 5.3 (Reynolds) Case 5.4 (PINE) Case 5.5 (Northumbria)
6. Patients involved at institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development. Patients given a formal position in the institution (eg Consumer Academic).	Patients involved in institutional decision making (eg student selection).	Downe et al., 2007 Happell & Roper, 2009 Simons et al., 2006	Case 6.1 (Comensus, UCLan) Case 6.2 (Leeds) Case 6.3 (Northampton) Case 6.4 (UNTRAP)

5.2 The outcomes of patient involvement

A consistent theme in the reviews on patient involvement is the lack of clear and measurable educational outcomes. Towle et al. (2010) have identified a variety of limitations to the literature. Most studies are descriptive and few interventions have been rigorously evaluated. Some evaluation of short-term outcomes for a small subset of initiatives is reported (primarily teaching of clinical skills), but few of these studies had rigorous experimental designs.

Interventions are usually described only once in the literature, soon after implementation (often of a pilot project) along with preliminary evaluation data (usually student satisfaction and patient views).

Overall, the quality of the literature is generally low as assessed by accepted criteria such as those of Best Evidence Medical Education (BEME) for quantitative studies, or Côté and Turgeon (2005) for qualitative studies.

The review by Morgan and Jones (2009) provides a good summary of the state of the art, although their review is limited to studies from the UK.

Most of the 41 papers they reviewed included some formal evaluation, except those that described patient involvement in curriculum design. There were no attempts to demonstrate an impact on the students who subsequently took these courses.

The studies that included an evaluation component generally captured the views of students and patients but not of the professional teachers. Using Kirkpatrick's four-level model of evaluation (Kirkpatrick, 1996), Morgan and Jones (2009) identified that:

– most papers provided data at level one (learner perceptions)
– four papers reported evaluation data at level two (measured changes in attitudes, skills and knowledge)
– one at level three (change in behaviour)
– one at level four (benefit to service users).

They conclude:

'despite a limited and weak traditional evidence base for impact on students' knowledge and practice, both students and service users identify benefits from engagement.'

Methodological weaknesses and the lack of specificity of objectives or intended outcomes, as well as their diversity, make it difficult to draw strong general conclusions about the effectiveness of patient involvement. Some of the recurring themes or more notable studies are identified below.

Learners' perspectives

Benefits

Most studies report high learner satisfaction with patient involvement (Morgan & Jones, 2009). Students identify benefits such as perceived relevance, enhanced understanding of patient perspectives, enhanced communication skills, increased confidence talking to patients and learning in a non-threatening environment (Jha et al., 2009).

Students report increased confidence and reduced anxiety in learning clinical skills from patient teachers, as this approach creates a safe learning environment for students to practice skills (especially intimate examinations) (Jha et al., 2010). Patient teachers are also able to provide immediate and more in-depth feedback to students than busy clinical preceptors. Comparison of student perceptions as reported in pre/post programme questionnaires indicate:

– students become more sensitive to the needs of vulnerable populations
– assumptions and attitudes improve significantly in relation to chronic illness, disabled children, family involvement, mental illness and senior care (Towle et al., 2010).

Independent verification of these perceptions is lacking. In objective comparative studies, students have been found to learn physical examination skills equally well from patient teachers as from physicians (Raj et al., 2006).

Few papers report student learning beyond the post-encounter evaluation (Morgan & Jones, 2009), but there is evidence that teaching by patients has a lasting impact in the areas of technical skills (Coleman et al., 2003), interpersonal skills, empathic understanding and developing an individualised approach to the patient (Klein et al., 2000; Wood & Wilson-Barnett, 1999).

Studies of effects on subsequent practice are rare. In one follow-up study of health professionals in a MA Community Mental Health course, all participants could describe how their practice had developed to enhance user involvement. A higher proportion of their service users, compared with a control group, reported good user-centred assessment and care planning (Barnes et al., 2006).

Concerns

Few disadvantages have been documented, compared with the benefits. The few studies in which students reported a negative experience were mostly following sessions with people with mental health problems, and were associated with

perceived antagonistic attitudes, unbalanced views, lack of representativeness and mixed views on the usefulness of feedback received (Morgan & Jones, 2009).

Other studies report that students are sometimes concerned about becoming a burden to patients. Patient attachment and mentorship programmes provide the first real, long-term exposure that students have to patients and this can be emotionally testing, especially if the patient-partner's health deteriorates. Faculty support for students in these programs and formal closure of the student-patient relationship are helpful. In the clinical years some students find it difficult to find time to spend with their patient mentors.

Patients' perspectives

Benefits

Studies report overwhelming benefits for patients and no negative effects (Morgan & Jones 2009). Patients feel their experiential knowledge of illness and the healthcare system should be included in medical education. Patients like to give something back to the community and feel their experiences can benefit future health professionals and patients (Stacy & Spencer, 1999). Patients report specific therapeutic benefits, such as raised self esteem and empowerment, development of a coherent 'illness narrative', new insights into their problems and deeper understanding of the doctor-patient relationship (Walters et al., 2003). Senior mentors enjoy the companionship of students. Patients generally feel well treated by students. Most programmes have largely positive feedback from patients, with most wanting to be repeatedly involved.

Concerns

Anxiety reported by patients starting their new role include concerns about revisiting negative experiences, being judged by students, and how truthfully their experiences will be represented when students write up assignments. Consent and confidentiality are major concerns for patients

and carers. These are addressed by appropriate preparation and orientation: clearly explaining the purpose and importance of their involvement, obtaining informed consent, limiting medical information provided to students to what is necessary to their learning, and providing strict guidelines about confidentiality (Towle et al., 2010). The potential for exploitation of people's goodwill has been raised (Stacy & Spencer, 1999) and occasional evidence of negative consequences has been documented, for example in relation to mental health (Livingston & Cooper, 2004) and intimate examinations (Jha et al., 2010).

Professionals' perspectives

Benefits

In general, health professionals involved in 'patient as teacher' programmes are pleased with the results. They feel that students have valuable learning experiences, are exposed to important patient issues, are enabled to see the patient's perspective, and gain valuable patient interaction skills. Trained patients can teach and assess as reliably as physicians. The faculty enjoys being involved as facilitators.

Concerns

No specific negative impacts on health professional educators have been documented. Some studies report that professionals have negative attitudes about involving patients, most frequently related to patients with mental health problems (Livingston & Cooper 2004). There are times when service users' views differ from those of the professionals and there is conflict over whether their views should be balanced, clarified or corrected. Some faculty perceive that their own expertise may be devalued. Having time to devote to these programmes is also of concern.

Some physicians have expressed concern about possible harmful effects on patients, such as emotional wellbeing and physical stamina, but the little research on this topic is inconclusive (Gecht, 2000). Some have the perception that

patients chosen by their doctors may either feel obligated to the commitment or conversely feel the commitment entitles them to preferential treatment, thus blurring professional boundaries (Walters et al., 2003).

A summary of the topics addressed, and main issues raised by literature reviews published in the last decade is provided in table 2.

Table 2: Summary of topics addressed and issues raised in the major literature reviews published in the last decade (after Spencer & McKimm, 2010)

Authors	Date	Scope	No. of articles	Topics addressed or issues raised
Spencer J et al.	2000	Selective literature review: medical education	18	– Theoretical reflections about potential educational benefits. – Framework for promoting discussion (the 'Cambridge Framework'). – Research needed into strengths and weaknesses of different approaches, and 'added value' of real patient contact.
Wykurz & Kelly	2002	Literature review: medical education	23	– Diversity of roles, settings and approaches identified. – Benefits for learners, patients and trainers. – Need for appropriate support, training and remuneration.
Repper & Breeze	2004	Systematic review: health and social care professionals, mainly mental health	38	– Small scale qualitative evaluations; focus on process not outcomes. – Tentative evidence of educational benefit. – Concerns: preparation, remuneration, power imbalance. – Commitment required at organisation/systems level. – Further research needed into impact.
Morgan & Jones	2009	Systematic review: health and social care professionals	41	– Benefits to students and patients but little evidence of change to practice. – Quality of research variable. – Further development of evaluation methodologies required.
Jha et al.	2009	Systematic review: medical education, excluded 'well trainers'	47	– Rationale for involvement. – Limited evidence of long-term effectiveness of interventions. – Ethical issues, psychological impact and influence on policy poorly explored.

Continued...

Table 2: Summary of topics addressed and issues raised in the major literature reviews published in the last decade (after Spencer & McKimm, 2010) *continued...*

Authors	Date	Scope	No. of articles	Topics addressed or issues raised
Towle et al.	2010	Comprehensive review: health and social care professionals	Not stated; database of ~300 papers	– Wide range of approaches, models, programmes. – Need for partnership. – Spectrum of involvement taxonomy proposed. – Detailed research agenda proposed.
Jha et al.	2010	Systematic review: healthcare professionals	65	– Specifically focussed on intimate examinations. – Evidence of short-term benefits. – Rationale and logistics of involving patients and volunteers. – Psychological impact (both learner and trainer) not well explored.

5.3 Policy and guidelines

A number of policy documents, guidelines and 'how to' articles informed our inquiry. These were:

– General Social Care Council. *Social Work Education in England: listening, learning, shaping*. London: General Social Care Council; 2007. Available at: www.gscc.org.uk/cmsFiles/Publications/GSCC_SWEG_Quality_Assurance_Report_2006.pdf
– Levin E. *Involving service users and carers in social work education*. Resource Guide No 2. London: Social Care Institute for Excellence; 2004. Available at: www.scie.org.uk
– Department of Health. *Requirements for social work training*. London: Department of Health; 2002.
– General Medical Council. *Tomorrow's doctors 2009*. London: General Medical Council; 2009 (and draft supplementary guidance about patient and public involvement in medical education).
– Tew J, Gell C, Foster S. *Learning from experience. Involving service users and carers in mental health education and training*. Nottingham: Higher Education Academy/NIMHE/Trent Workforce Development Confederation; 2004. Available at: www.mhhe.heacademy.ac.uk/silo/files/learning-from-experience-whole-guide.pdf
– British Medical Association, Medical Education Subcommittee. *The role of the patient in medical education*. London: British Medical Association; 2008. Available at: www.bma.org.uk/images/roleofthepatient_tcm27-175953.pdf
– Trent Strategic Health Authority. *Principles for practice. Involving service users and carers in healthcare education and training*. Mansfield: Trent Strategic Health Authority; 2005.
– Hasman A, Coulter A, Askham J. *Education for partnership. Developments in medical education*. London: Picker Institute; 2006.

– Howe A, Anderson J. Involving patients in medical education. *British Medical Journal* 2003; 327: 326-328.
– Rees C, Knight LV, Wilkinson CE.'User involvement is a sine qua non, almost, in medical education': learning with rather than about health and social care service users. *Advance in Health Sciences Education* 2007; 12: 359-390.
– Farrell C, Towle A, Godolphin W. *Where's the patient voice in health professional education?* Vancouver: University of British Columbia; 2006. (ISBN 0978202805)

Although originating from a variety of contexts, serving different purposes and derived from different, if overlapping, sources (including the literature, 'stakeholder' workshops, field research, conferences), there is remarkable consistency in the issues raised and key messages provided. These will be picked up again in Section 8: Discussion and conclusions.

5.5 Theory

Very little of the literature about patient/user involvement in education is informed by theory. Katz et al. (2000) and Rees et al. (2007) take a socio-cultural stance to explore issues surrounding how students learn 'with' rather than simply 'about' patients. Socio-cultural learning theories (such as 'situated learning' (Lave and Wenger, 1991), with its notions of legitimate peripheral participation and communities of practice), offer insights into issues such as power relationships, identity, access and activities that are highly pertinent to considerations about patient/user involvement.

Rees et al. (2007) make 22 recommendations based on their research.

Bleakley and Bligh (2008) propose a theoretical model of collaborative knowledge production. This is based on theories of text, identity construction, and work-based learning in which the prime locus for knowledge production is the student's reading of the patient's condition in collaboration with the patient.

In this radical model, the teacher's role shifts from one of knowledge production to genuine facilitation, and the process of education becomes a 'mutually beneficial dialogue supported by experts'.

The literature on engagement and participatory democracy was not consulted due to time pressures, but it was clear that in some settings the concept of involvement is felt to perpetuate the hegemony of professional control of education (and practice), and that the necessary philosophy and practice should be one of genuine partnership and inclusivity.

These examples provide glimpses of how the active involvement of patients could inform the development of a new educational paradigm in which students, teachers, and patients can create new knowledge and novel solutions to healthcare problems by learning together in partnership.

5.5 Who are the patients/users?

A final issue in this section relates to the thorny question of identity, and in particular representativeness. It is easy to forget that the vast population of people who might fall under the general headings of 'patient' or 'user' are by no means homogeneous; indeed diversity is the norm. Patients/users do not think alike any more than professionals do, yet much of the literature on involvement sidesteps this issue.

It also, if only by omission, seems to treat all users, carers, survivors, clients, patients and so on as the same. Concerns are also frequently expressed about representation. In particular about involving people with a single issue or an axe to grind.

Charlotte Williamson of Picker Institute, Europe proposes three broad categories of patient. These are based on consideration of what she calls 'the patient side' of healthcare, the experience of and knowledge domains they use (Williamson, 2007).

Individual patients can describe their own experience but cannot necessarily speak for others.

This raises questions about representativeness and begs the need for eliciting concerns from this group using survey methods.

Patient group members usually do know about the experiences of others like themselves, but may still have a narrow perspective. Consulting all relevant groups in a locality is important.

Finally, patient representatives or advocates usually have broader experience, perhaps of working with several groups, wider knowledge about issues at strategic and policy levels, and of 'the bigger picture'. Ideally consultation with patients should involve all three categories using appropriate methods. In Williamson's words:

'The patient side of healthcare is complex but not mysterious. Consulting the 'right' patients can be feasible and rewarding.'

(Williamson, 2007)

6 Case studies

These case studies were identified from the literature or initiatives known to the authors through established networks, or both. The selection aims to represent different levels of the 'Spectrum of Involvement' (Appendix 4), and covers a range of disciplinary backgrounds, levels of education, geographical locations and approaches.

6.1 Introduction

The case studies are organised under the following levels:

Level 1 – Patients involved in creating learning materials used by faculty.

Level 2 – Standardised or volunteer patient in a clinical setting.

Level 3 – Patient shares his or her experience with students within a faculty-directed curriculum.

Level 4 – Patient-teacher(s) are involved in teaching or evaluating students.

Level 5 – Patient teacher(s) as equal partners in student education, evaluation and curriculum development.

Level 6 – Patients involved at institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development.

Each comprises information under these headings:

– Description and history
– Funding and structure
– Programme evaluation
– Programme contact
– Other initiatives and additional information
– Outputs and resources.

6.2 Case studies

Level 1 – Patients involved in creating learning materials used by faculty

Case study 1 – The Voices of Survivors Documentary, Oregon Health and Sciences University, Division of General Internal Medicine and Geriatrics, USA

Description and history

Dr Nicolaidis created the documentary in 1998–1999 partnering with domestic violence advocates, abuse survivors and local artists. Twenty-one domestic violence survivors were interviewed about what they wanted physicians to understand about life in an abusive relationship, and what they wanted them to do as part of their healthcare. Qualitative analysis identified four main themes:

– domestic violence is universal
– it is more than just physical assaults
– it is all about power and control
– it affects the entire family.

Themes were also identified about what survivors want physicians to do to help them. Recommendations were organised around five common situations in which survivors felt they could use help from physicians.

These situations were when a survivor:

– has not recognised the abuse
– is not ready or able to discuss the abuse
– is choosing to remain in an abusive relationship
– has suffered an acute assault
– has left the relationship but not yet healed.

Interview excerpts representing each of the identified themes and recommendations were used to create the 30-minute video.

Funding and structure

The documentary was created using funds from the Robert Wood Johnson Foundation. It is now marketed and distributed by Family Violence Prevention Fund and the American College of Physicians. The documentary is unique in that it relies almost exclusively on survivor narratives, not expert opinion. It is a collective survivor-teaching tool where survivors play a role as educators. Thousands of copies have been distributed to medical schools, residency programmes, clinics, and community organisations. At Oregon Health and Science University, the video is currently being used as part of a course on Principles of Clinical Medicine and is followed by specific skills training. It is regularly used at medical schools and residency programmes across the country.

Programme evaluation

The documentary, along with a workshop based on its companion guide, was used in a study funded by the Northwest Health Foundation in 2004 to assess the effectiveness of the Voices of Survivors programme in improving empathy, respect for patient autonomy, confidence, knowledge and self-reported assessment behaviour. Thirty-one unaffiliated primary care practices in Washington County participated.

Comparison of surveys before and after a 2-hour workshop, including the 30-minute video, showed improved employee's knowledge, attitudes, empathy, and self-reported assessment behaviours about intimate partner violence.

Programme contact

Dr Christina Nicolaidis, Associate Professor of Medicine and Public Health, Oregon Health & Science University. nicolaid@ohsu.edu

Other initiatives and additional information

Dr Nicolaidis is also working on a website that will provide patient narratives of autistic adults. This information (similar to documentary format) will give physicians better insight into the type of care patients with autism need and expect to receive from their physicians.

Outputs and resources

The Voices of Survivors documentary.

Nicolaidis C. The Voices of Survivors documentary. Using patient narrative to educate physicians about domestic violence. *Journal of General Internal Medicine* 2002; 17: 117-124.

Nicolaidis C, Curry MA, Gerrity, M. Measuring the impact of the Voices of Survivors program on health care workers' attitudes towards survivors of intimate partner violence. *Journal of General Internal Medicine* 2005; 20: 731-737.

Nicolaidis C, Curry MA, Gerrity M. Health care workers' expectations and empathy towards patients in abusive relationships. *Journal of the American Board of Family Medicine* 2005; 18: 159-65.

Nicolaidis C. Lessons about recruiting primary care practices to domestic violence trainings. *Family Violence Prevention and Health Practice* 2005; 1: 1-8.

Level 2 – Standardised or volunteer patient in a clinical setting

Case study 2 – Storytelling: a clinical application for undergraduate nursing students, Creighton University School of Nursing, Omaha, Nebraska, USA

Description and history

In 2005, Creighton University School of Nursing (CUSON) in Omaha, Nebraska, selected five faculty members to design and implement a model for teaching healthcare management in a community setting. Each was assigned a community health nursing faculty mentor. The goals were to cross-educate acute care faculty on how to provide holistic care to patients, and incorporate what faculty learned into their acute care clinical experience with students. During the two-year project faculty conducted educational sessions and spent an average of 40 clinical hours in different community settings.

Funding and structure

CUSON received a Helene Fuld Trust grant for this two-year project. Storytelling was the main theme discovered in the process of this research. Related themes were listening, partnership, reciprocity and solidarity. Storytelling was later used as a teaching tool and incorporated into nursing courses to teach students how to collect data that are current and relevant to their patients. Storytelling techniques varied depending on the course in the curriculum. Student-patient interaction occurs mostly in the hospital. Patients share their experiences with the student within guidelines set out by the faculty. Each student interacts with two patients over 16 hours of clinical placement, and is required to write a story, initially based on the patient's chart.

They are then asked to write a second story after they have interacted with the patient in person. The goal is to show the students that chart depiction of the story is not always correct.

Another way that storytelling is incorporated at CUSON is in the Professional Patient Safety course in which students write their own patient safety stories. All the stories are later compiled into a book that is distributed at the end of the course.

What makes this initiative unique is the way it changes student perspectives on how to work with patients. It shifts focus from conditions to individual patients and their personal stories. It helps to establish relationships between patients and health professionals.

Programme evaluation

Feedback from the students after their rotations has been positive. Most of the evaluations were done through journaling and focused mainly on students, although no long-term impact evaluation has been carried out. Patient evaluations might be the future focus of this initiative.

Programme contact

Dr Amy Abbott, Creighton University School of Nursing.

Outputs and resources

Schwartz M, Abbott A. Story telling: a clinical application for undergraduate nursing students. *Nurse Education in Practice* 2007; 7: 181-186.

Level 3 – Patient shares his or her experience with students within a faculty-directed curriculum

Case study 3.1 – Senior Teacher Educator Partnership (STEP), University of Missouri-Columbia School of Medicine, USA

Description and history

The primary goal of the STEP programme is to engender positive student views regarding older people. It is one of many ongoing initiatives in the medical school that are developed around education for patient-centred care. This voluntary programme links first-year medical students with community-dwelling seniors, through planned luncheons and group educational sessions. These sessions take place eight times a year on health topics interesting to the elderly partners and students. In addition, students and seniors arrange social activities on their own.

Funding and structure

The programme was initiated with funding in 2001 from the John A. Hartford Foundation in collaboration with the Association of American Medical Colleges. It is sustained by support from the Donald W. Reynolds Foundation and the Robert M. Heyssel, MD, Endowment. The initiative is now partly funded by the medical school and through some remaining grant funding.

There is a coordinator who fosters relationships with the senior community as well as nurturing a large network of STEP members. The programme has a very good reputation amongst community and faculty, and is strongly supported by the medical school. The voluntary feature of the programme makes the initiative unique and students taking it are committed to their STEP partners. Student participation is recognised by a formal letter that becomes part of their performance evaluation at the end of the fourth year of medical school.

The value of the programme lies in the relationship that students develop and retain outside of formal activities. Many students stay in touch with STEP members even after graduation. Development of this sort of relationship cannot be taught in the classroom.

Programme evaluation

Surveys, journals and focus groups were used to evaluate the programme. Main themes identified were:

- the generations have a lot in common
- there is a value in viewing healthcare through the eyes of the seniors
- aging is a very individual process
- one can learn strategies to deal with experiences from other generations.

There was also evaluation through all four years of medical school and into residency. It indicated that the programme has an impact on how students view the patient population they will serve.

Programme contact

Dr Kimberly Hoffman, Associate Dean, Educational Evaluation and Improvement, University of Missouri-Columbia, School of Medicine.

Other initiatives and additional information

The 'Introduction to Patient Care' course uses simulations in which students practice having difficult conversations with standardised patients. The school selects standardised patients from the pool of contacts based on the case studies in a specific course.

Outputs and resources

Hoffman KG, Gray P, Hosokawa MC, Zweig SC. Evaluating the effectiveness of a senior mentor program. *Gerontology & Geriatrics Education* 2006; 27 (2): 37-47.

Case study 3.2 – Family project as part of 'Medicine, Patients and Society' programme, Tel Aviv University Medical School, Israel

Description and history

The programme aims to teach students the importance of context and interaction in patient care. It exposes students to a real patient-family-doctor interaction using narrative-based methods to encourage reflective learning. The programme started in 2000 in Tel Aviv University Medical School and was driven by Dr Anat Gaver who knew of similar programmes in the UK using families as teachers. The medical school in Tel Aviv is unique in that it has two groups of medical students, both Israeli, and American from New York. This programme is a powerful experience for medical students who interact with patients and their families; most have never been exposed to this kind of experience before.

Funding and structure

The medical school provides some salary and minor administrative costs associated with this initiative. Families that take part in the programme are involved on a voluntary basis and are recruited through various not-for-profit health organisations and doctors' offices. The main incentive driving family participation is that, following a negative experience in the medical care system, they have the opportunity to teach the future generation of medical professionals.

The course is entitled 'Disease and Illness in Context – a Long-Term Follow Up of a Family'. It is part of the 'Medicine, Patients and Society' (MPS) programme that spans all six years of medical school and attempts to integrate behavioural science, humanities, life sciences and clinical medicine 'seamlessly'. Its overall goal is to help medical students become humanistic physicians. One of the programme's challenges is to find families that fit course objectives. In the second year, medical students have five meetings with the assigned family and have the chance to learn about specific conditions, see how the family copes with the patient and their circumstances.

Students use reflective writing to learn from their experiences. The Medical Connections course in the first year also gives patient exposure to students outside of the medical setting. Students have an opportunity to go to schools, shelters, addiction centres, places for the homeless, and health sites to learn how people live their lives with their illnesses.

Programme evaluation

Analysis of students identified the following themes:

– becoming 'family sensitive'
– building and improving communication skills
– adopting a nonpatronising and a nonjudgmental attitude
– developing reflective skill and personal growth
– creating a future professional model
– experiencing and appreciating continuity of care
– questioning intrusiveness.

For families, the main outcome was the ability to influence future doctors. The students that went through this programme were more comfortable and knowledgeable, and their perception of stereotypes changed.

Programme contact

Dr Eva Schlank (evasch@clalit.org.il) and Dr Anat Gaver, Tel Aviv University, Israel

Outputs and resources

Gaver A, Borkan JM, Weingarten MA. Illness in context and families as teachers: a year-long project for medical students. *Academic Medicine* 2005; 80 (5): 448-51.

Borkan JM, Weingarten MA, Schlank E, et al. A model for educating humanistic physicians in the 21st century: the new Medicine, Patient, and Society course at Tel Aviv University. *Educ Health* 2000; 13: 346-355.

Case study 3.3 – Teaching students about intellectual disability, St George's University of London, UK

Description and history

At St George's Hospital Medical School (as it was then called), 30 years ago, teaching about intellectual disability (ID) in the undergraduate medical curriculum consisted of visits to long-stay institutions. This was essentially to observe patients and receive some formal teaching about conditions. This was felt to be voyeuristic and tokenistic and an entirely inappropriate and unsatisfactory learning experience.

A new initiative introduced by Professor Sheila Hollins and colleagues involved people with IDs coming into the medical school to talk with students in small groups, followed by a visit to a residential home to talk with residents.

Following a staff workshop, this developed into involvement with the Strathcona Theatre Company (see BMJ 1996; 312: 1427) of professional actors with IDs, the first of its kind in the UK. For several years Strathcona ran regular workshops for third and fourth year medical students as part of a psychiatry attachment. Feedback from students, staff and Company members alike was generally very positive.

Unfortunately, for various reasons, mainly problems with funding, Strathcona folded, but two newly established theatre companies (Baked Bean Theatre Company and Access Simulations) were able to contribute to the next phase in the initiative's evolution. This was to train some of the actors to work as simulated patients.

An objective structured clinical examination (OSCE) station had been introduced to test students' skills in establishing informed consent with a person with IDs, initially played by simulated patients without intellectual disability.

This was felt to be inappropriate:

'Simulated patients with ID (SPIDs) with genuine language limitations and an authentic experience of coping with life as a disabled adult can expose communication problems in a way that even the most skilled non-disabled actor cannot.'

(Thacker et al., 2007)

The SPID portrays a patient with a particular medical and social history, including a set of pre-agreed symptoms. Since 2001 SPIDs have also been used in the psychiatry final exams. A DVD and a set of guidelines for ethical working with people with IDs was eventually produced and distributed to all medical schools in the UK. A website (Understanding Intellectual Disability & Health) was also developed.

Current teaching about IDs for medical students involving people with experience at St George's comprises:

– a communication skills workshop for second year students
– an attachment spread over five weeks (half a day per week) during the fourth year as part of a primary care attachment (community disability)
– actors from the Baked Bean Theatre Company role playing patients with IDs in simulated scenarios that involve issues such as seeking informed consent and undertaking health screening assessment
– students then visit people with IDs in their homes to find out about their lives and carry out health screening and assessment.

Funding and structure

The initiative has full institutional support and two people with IDs are employed on a part-time basis. They have several roles, including acting as training advisors and as co-researchers, their primary role being teaching. There is administrative and secretarial support.

Programme evaluation

Feedback has been generally positive before and after sessions. Students who have participated in training with SPIDs have:

– positive attitudes about the competence of people with IDs to participate in consultations
– found working with SPIDs a very valuable experience
– been stimulated to further investigate a range of topics about IDs
– identified a wide range of previously undetected health problems in real patients with IDs in the community.

Programme contact

Professor Sheila Hollins, St George's University of London, shollins@sgul.ac.uk

Other initiatives and additional information

The Baked Bean Theatre Company is a collective of actors with intellectual disabilities who devise and produce their own plays and films, which they perform in and around London. See website at: www.acttoo.com/bbtc.html
or contact ican@acttoo.com

Access Simulations is a small organisation which provides authentic skills training by people with intellectual disabilities, see website at: www.access-simulations.co.uk
or contact athacker@access-simulations.co.uk to discuss requirements.

Outputs and resources

Hall IS, Hollins S. The Strathcona Theatre Company: changing medical students' attitudes to learning disability. *Psychiatric Bulletin* 1996; 20: 429-430.

Thacker A, Crabb N, Perez W, Raji O, Hollins S. How (and why) to employ simulated patients with intellectual disabilities. *Clinical Teacher* 2007; 4: 10-14.

Owen K, Butler G, Hollins S. *A new kind of trainer: how to develop the training role for people with learning disabilities*. London: Gaskell; 2004.

Understanding Intellectual Disability & Health website: www.intellectualdisability.info
This is described as an 'ideal learning resource for medical, nursing and other healthcare students' and contains many resources that would be useful not only for students but also practitioners, including links to other sites, tips and guidance (eg about effective clinical communication).

DVD and accompanying manual: *Employing simulated patients with intellectual disabilities*. Cost £12 each, including postage and packing. For further information contact: Penelope Parkinson at St George's University of London, pparkins@sgul.ac.uk

Another output has been the Books Without Words (BWWs) series, edited by Professor Hollins. BWWs are full-colour picture books that address some of the problems in understanding experienced by people with intellectual and communication difficulties. See the website: http://www.intellectualdisability.info/how-to../ books-beyond-words-telling-the-whole-story-in-pictures/

Case study 3.4 – The Keeping Families Healthy programme at the University of Florida College of Medicine, USA [The current title of the course is Interdisciplinary Family Health]

Description and history

In 1998 the programme placed 85 medical students in direct partnership with volunteer families from the community. The families openly share their healthcare beliefs and practices with their assigned students. Families get an information package on the course with faculty objectives that explain the family role and expectations for this initiative.

Funding and structure

This initiative was funded for three years, from 1995, by the Pew Foundation and was initially designed for medical students only. Later additional funding was received from Merck. When the grant funding ran out, the initiative was picked up by University of Florida College of Medicine, USA and is now supported through core budgets.

The present two-semester required course offers first-year medical, dental, nursing, physical therapy, pharmacy, nutrition, and veterinary students the opportunity to integrate prevention, service, and humanism into the established educational curriculum. The main outcomes for learners include:

– learning to work as healthcare team members
– improved communication skills
– increased knowledge of family health-related issues
– knowledge of community resources, local and national.

Students have opportunities to interact with families who have volunteered to serve in partnership with the College of Medicine faculty as community lay teachers. Community-based learning and home visits expose students to personal travails (for example, lack of financial resources) in a way that cannot be addressed in traditional settings. Home visits provide an opportunity for pre-clinical students to have an active rather than passive role in their education.

The course objectives have been to teach students about family health, improve communication, and provide services for the community. Online resources that are available for this course support 475 students, 80+ faculty and 160 families in the community each year.

Students are split into groups and four different families are introduced in each group. The school has a base of about 90 to 100 families with additional volunteers being recruited through support groups, community centres, churches, and so on.

Programme evaluation

The course is modified annually in response to feedback from students, faculty and families garnered through surveys, interviews, focus groups, and reflective journal writing. Feedback has been increasingly positive as the course has evolved. This service learning experience has helped to promote positive patient–physician relationships between students and their assigned families. The volunteer families that teach in

the course and are the 'patients' have expressed appreciation for the opportunity to teach future providers about what is most important to them when they engage in healthcare. This includes having someone to listen to them, hear their concerns, and demonstrate a caring attitude. Long-term evaluation has been carried out recently, but analysis of the data is not yet complete.

Programme contact

Dr Rhondda Waddell, Associate Director, Office of Generalist Education

Program for Interdisciplinary Education, University of Florida College of Medicine, USA

Other initiatives and additional information

Dr Waddell has been involved in this initiative since 1996 and it has been one of the most rewarding experiences to develop it and see it grow. One of the constant challenges is finding ways for the university and community to interact together effectively. Harvard has a similar programme in their medical school where students see patients in the hospital and then follow up with them in their home setting.

Outputs and resources

Waddell RF, Davison RA. The role of the community in educating medical students: initial impressions from a new programme. *Education for Health* 2000; 13 (1): 69-76.

Burg MA, Waddell R. The Keeping Families Healthy program: collaborative training in the 'real world' of family health (Collaboration In Action). *Families, Systems & Health* 2003; 21(2): 227-232.

Davidson RA, Waddell R. A historical overview of interdisciplinary family health: a community-based interprofessional health professions course. *Academic Medicine* 2005; 80 (4): 334-338.

For additional resources on this programme please visit: http://families.health.ufl.edu

Case study 3.5 – Community-based undergraduate project, Newcastle University, UK

Description and history

This initiative was first introduced in the mid-1970s and was one of the first of its kind in UK medical schools. It is a key component of a course called 'Medicine in the Community' that runs through the first two years of the undergraduate medical course. It is an integrated course, with a life cycle theme, including contributions from primary care, public health, medical sociology, health psychology and child health. This particular project, called 'The Patient Study', runs in the second year and involves an attachment to a person with a long-term condition living in the community who is usually under the care of the student's GP group tutor.

The project has developed in response to student and tutor feedback, and emerging issues in both policy and practice, though in essence the format has not changed substantially. Plans to increase vertical integration of the project are underway. It will link with further similar studies involving formal patient contact and associated teaching in both the community and hospital in the third year of the curriculum.

It will form a new curricular strand called 'The Long Term Condition Journey'. This mirrors developments in the way healthcare is increasingly conceptualised in the UK NHS (for example, with integrated care pathways).

Funding and structure

Over a six-month period, students in pairs visit the patient in their home three or four times and are supported by several seminars in the medical school. They also make contact with a relevant community agency outside the formal healthcare sector (for example, a voluntary sector patient support group). The broad aims of the project are for the student to observe the impact of a long-term condition on a patient (and their family/carers) and to consider the biopsychosocial factors that influence the impact. It is also a focus for integrating learning in the different strands of the course. The project is assessed by a 5,000 word project report that includes a reflective element. It also links with a literature review on a topic related to the patient's problem.

It has endured because it has had institutional support from the start, is embedded in the undergraduate curriculum and is seen to address important core learning outcomes. It has also been championed by the course director. Being a core part of the curriculum, the project has been supported by core funding.

Apart from their interactions with students, patients have not so far been actively involved in managing or developing the project. Patients and carers are not paid for their involvement. Students are also attached to a pregnant woman in the community during their first year. As with the Patient Study, they explore impact, in this instance of a pregnancy and birth of a child, on the person and their family, with serial contacts over a period of months.

Programme evaluation

Evaluation of the course from both student and tutor perspectives has generally been very positive. Long-term impact has not been evaluated.

A qualitative research study of the view of patients about their role as teachers, involving interviews with 20 patients, has identified two major themes (Spencer and Stacy, 1999).

First, many saw themselves as having an active teaching role (as experts in their condition, examples of the conditions and facilitators of professional skills development). Second, many benefits were identified, including the opportunity to talk and give something back, and learn more about their condition. Few disadvantages were highlighted but the potential for such a situation to be exploitative was discussed. The need for thorough briefing was highlighted.

Programme contact

Dr Maryanne Freer, Senior Medical Tutor, School of Medical Sciences Education Development, Newcastle University, 16/17 Framlington Place, Newcastle upon Tyne, NE2 4HH, UK. Maryanne.freer@ncl.ac.uk

Other initiatives and additional information

Most UK medical schools have introduced similar initiatives. These comprise attachment of medical students over a period of time to a person in the community with a particular health problem, or to a pregnant woman. Two such programmes are:

– Dundee Medical School: The 'Doctors, patients and communities' theme runs through the first three years of the undergraduate medical course and involves serial interactions with a person with a long-term condition in their own home (see Muir, 2007)
– Glasgow Medical School: The Longitudinal Care Project has been running since 1998 and gives third-year medical students the opportunity to experience the clinical care of a patient with chronic illness over a six-month period. The patient's commitment involves several interviews and physical examination, consenting to access to their medical records and agreeing to their case being presented and discussed (see Barton, 2009).

Outputs and resources

Stacy R, Spencer J. Patients as teachers: a qualitative study of patients' views on their role in a community-based undergraduate project. *Medical Education* 1999; 33: 688-694.

Foster DP, Drinkwater CK, Corradine A, Cowley K. The family study: a model for integrating the individual and community perspective in medical education. *Medical Education* 1992; 26: 110-115.

Muir F. Placing the patient at the core of teaching. *Medical Teacher* 2007; 29: 258-260.

Barton P (2009) Evaluating 10 years of the longitudinal care programme. *Clinical Teacher* 2009; 6: 38-43.

Case study 3.6 – Learning from lives – a model for health and social care education in the community, Warwick Medical School, UK

Description and history

This initiative was originally developed at the Medical School in Leicester. The programme focused on inequalities in health and its original aim was:

'to use the social and behavioural sciences and the humanities to enable students to gain a richer understanding of the individual patient; to show the range and roles of professionals working to meet the health needs of the population; to develop in the students an understanding of the contribution of economic, practical, and environmental factors in the causes and prognosis of illness and in the use of services; and to provide learning experiences and an exposure to diverse common health problems not normally seen in secondary healthcare.'

The programme was based in the community in an inner-city setting, and involved students learning in a multi-agency environment. Tasks included interviewing people in their own homes, and meeting with representatives of agencies with whom the patients were involved.

Warwick University joined Leicester in partnership in 2000 to form Leicester-Warwick Medical School. In 2006 the two institutions separated creating Warwick Medical School. The programme is still delivered true to original aims but has been adapted to Warwick Medical School's situation.

Funding and structure

Early in the first year of the graduate entry course, as part of the 'Health and Community' module, students meet patients in their own homes, including a parent, someone in midlife and an older person. This is part of a 'life span' theme. The students, as in the original model, also meet people from agencies involved with the individuals' care. This may include health and social care professionals who know them.

Later in the course, at the start of phase II (see: www2.warwick.ac.uk/fac/med/study/ugr/course), during the 'Learning from Lives' block, students again meet people in the community. At this point, the aim is to provide a practical, in-depth understanding of the nature and effect of illness and impairment on people's lives, and the way in which the individual family and society react towards disabled people.

There is an interprofessional dimension to the learning (for example, community placements are run by community nurses). Service users are involved in the induction sessions.

This teaching is part of the core curriculum and as such attracts institutional support and core funding. The users who facilitate the induction come from UNTRAP (see case study 6.4)

Programme evaluation

Evaluation of the course from the points of views of all involved has been consistently positive.

There has been no long-term evaluation of impact.

Programme contact

Dr Janet Furlong. janet.furlong@warwick.ac.uk

Other initiatives and additional information

N/A

Outputs and resources

Lennox A, Petersen S. Development and evaluation of a community based, multiagency course for medical students – descriptive survey. *British Medical Journal* 1998; 316: 596-599.

Anderson EA, Lennox AI, Petersen SA. Learning from lives: a model for health and social care in the wider community context. *Medical Education* 2003; 37: 59-68.

Jackson A, Blaxter L, Lewando-Hundt G. Participating in medical education: views of patients and carers living in deprived communities. *Medical Education* 2003; 37: 532-538.

Level 4 – Patient-teacher(s) are involved in teaching or evaluating students

Case study 4.1 – Participation of trained persons with arthritis in teaching medical students about musculo-skeletal exams, University of Texas, Southwestern Medical Center at Dallas, USA

Description and history

Building on the work of Dr Eric Gall in Arizona, who used arthritis patients as patient instructors, Ms Valerie Branch and Dr Peter Lipsky, developed an arthritis patient educator training programme called Patient Partners in Arthritis™ (PPIA).

The goal of this programme is to train people with arthritis in musculo-skeletal (MSK) anatomy, joint examination techniques and communication skills, and to prepare them to teach students and practising healthcare professionals the basics of MSK physical examination.

The initiative started in late 1980s, funded by a pharmaceutical company. In 2002, pharmaceutical support ended to this and similar initiatives in the USA and the financial responsibility shifted to institutions.

Funding and structure

Since the pharmaceutical funding ceased, the programme has contracted. However, the University of Texas, Southwestern Medical Center at Dallas, USA agreed to fund the initiative to teach a required second-year medical student class (200 students). Students in small groups are introduced to the MSK examination as part of a required 'Introduction to Clinical Medicine' course, and are taught joint examination by a trained arthritis educator after viewing a video. The programme has approximately eight or nine dedicated educators who have been involved in the training for many years. The services of the patient educator are also sometimes used by independent sites.

The school is very supportive of the programme, and is one of few sites that have continued with it.

Programme evaluation

Evaluation was carried out using pre and post surveys of medical students. The scores for the examination skills of those trained by the arthritis educator were compared with students who had not received the training. It was found that the intervention by arthritis educators improved the retention of information, confidence and examination skills of the second-year medical students significantly compared with the standard educational approach. The impact of the intervention persisted for at least two weeks. No long-term evaluation of impact has been performed.

Programme contact

Ms Valerie Klusas Branch, Faculty Associate, University of Texas, Southwestern Medical Center. valerie.branch@utsouthwestern.edu

Other initiatives and additional information

The Rheumatology Division also funds a programme that uses the same arthritis patient educators to counsel individual patients with arthritis at the arthritis centre. This programme has been in place since the mid-1990s.

Internationally, similar arthritis educator programmes continue to thrive because the shift in pharmaceutical funding was specific to the USA only. See case study 4.2 for a description of the initiative at the University of Toronto established by Dr Mary Bell.

Outputs and resources

Branch VK, Lipsky PE. Positive impact of an intervention by arthritis educators on retention of information, confidence, and examination skills of medical students. *Arthritis Care & Research* 1998; 11 (1): 32-38.

Branch VK, Graves G, Hanczyc M, Lipsky PE. The utility of trained arthritis patient educators in the evaluation and improvement of musculoskeletal examination skills of physicians in training. *Arthritis Care & Research* 1998; 12 (1): 61-69.

Branch VK, Lipsky PL. The use of trained arthritis patients in the instruction of the musculoskeletal examination. *Journal of Rheumatology* 1999; 26 (55): 52-55.

Branch VK, Nieman T, Lipsky PE. Positive impact of an intervention by arthritis patient educators on knowledge and satisfaction of patients in a rheumatology practice. *Arthritis Care & Research* 1999; 12 (6): 370-375.

Gruppen L, Branch VK, Laing TJ. The use of trained patient educators with rheumatoid arthritis to teach medical students. *Arthritis Care & Research* 1996; 9: 302-8.

Case study 4.2 – Patient Partners in Arthritis (PPIA) programme in Canada

Background and history

Funded by Searle Canada, the scientific underpinning for the impact of this programme on learners was established by Dr Mary Bell in the early 1990s. In a study with medical students and postgraduate trainees, she demonstrated that PPIAs improved the ability of learners to conduct the MSK physical examination by 33% and increased confidence by 75% in so doing. Retesting at one month post-training revealed maintenance of these newly acquired skills. Learners indicated that the PPIAs were competent and the opportunity to learn from 'real patients' who provide a one-to-one, practical, hands-on experience in a non-rushed, non-threatening atmosphere was highly valued. All learners recommended training from a PPIA for their colleagues and indicated a desire to participate again in a similar session. The results of this study were published in Academic Medicine in 1997.

Funding and structure

Refinement of the PPIA programme in Canada included:

– modifying training materials to meet Canadian standards (for example, adapting for two official languages)
– developing a quality assurance programme by standardising the training, testing and retraining
– expanding and establishing PPIA programmes at 13 of the then 16 Canadian medical schools.

Although institutional and collegial support for the programme evolved slowly, academics and healthcare professionals alike endorse its value in training and maintenance of competence. In recent years, mergers of Canadian pharmaceutical companies have resulted in a change in management of the PPIA programme and it is now owned, funded and coordinated by Pfizer, Canada.

Details of future goals can be obtained from Cynthia Jamison at Pfizer, Canada (see below).

Programme evaluation

The impact of being a PPIA has also been formally assessed. Benefits include:

– the development of self-confidence; improved self-esteem
– finding a positive support group; improving relationships with healthcare providers
– increasing knowledge of disease.

Overall this innovative educational programme has had a positive impact on the PPIAs through improved quality of life and an expanded role in the medical community.

Programme contact

Cynthia Jamison at Pfizer, Canada.
cynthia.jamison@pfizer.com

Other initiatives and additional information

Over the past 16 years, the programme has been incorporated into undergraduate, postgraduate and continuing education health professional programmes across Canada. Similar programmes have been established in the UK, France, Belgium and South Africa.

Outputs and resources

Bell MJ, Badley EM, Glazier RH, Poldre PA. A pilot study to determine the effect of patient educators on medical students' and residents' skills in joint examination. *Academic Medicine* 1997; 72 (10): 919.

Bell MJ, Poldre PA, Base C, Reiswig T, Myers J, Hamelin J, Wexler E (1999) The positive personal impacts of being an arthritis patient educator. American College of Rheumatology (ACR) 1999; November: 13-17.

Bell MJ, Poldre P, Wexler E, Lupton T, Base C (2004) The positive personal impacts of being an arthritis patient educator. American College of Rheumatology (ACR) Economic, Social and Psychological Impact of Arthritis Conference, October 16 2004, San Antonio, TX; 2004. (Poster)

University of Toronto Faculty of Medicine Annual Educational Achievement Event (2005). Getting Evidence into Practice: Trained Arthritis Patient Educators as a Vehicle for the Dissemination and Implementation of Cochrane MSK Reviews. Toronto, ON (Poster); 2005.

Oswald AE, Bell MJ, Snell L, Wiseman J. The current state of musculoskeletal clinical skills teaching for preclerkship medical students. *Journal of Rheumatology* 2008; 35 (12): 2419-2426. doi:10.3899/jrheum.080308.

Case study 4.3 – Patient instructors with arthritis take part in skeletal joint exam education of medical students and residents, Department of Family Medicine, University of Illinois, USA

Description and history

This programme was started by Dr Susan Perlman at Northwestern University Multipurpose Arthritis Center, Chicago, based on the pioneering work of Eric Gall in Arizona (see case study 4.1). Funded by a grant from the Multipurpose Arthritis Center in the 1980s, the programme used patient instructors with arthritis trained to conduct MSK examination and teach fellows in rheumatology and medical students. Both had a chance to interact with more than one patient educator with a different diagnosis. The patient educators also had an opportunity to provide their feedback. In the 1990s additional funds were obtained and Maureen Gecht became the patient instructor trainer and coordinator for the programme, and Dr Frank and Karen Connell provided training and created training materials. The latter obtained HRSA funding to start a MSK training programme for third-year medical students at University of Illinois, Chicago (UIC).

The patient instructors provided workshops for UIC medical students about eight times per year. Seminars and workshops that included programme evaluation were presented at national family medicine conferences.

The programme was maintained in the department for several years and then moved into the second-year medical student curriculum and continues to this day.

Further grant funding was obtained (from the Fund for the Improvement of Post Secondary Education) to expand the programme to provide MSK assessment skills to residents in five Chicago area family medicine residency programmes. After the funding ended, UIC and Cook County family medicine residencies continued the programme for approximately five years. However, due to patient instructor illness and death, lack of a physician mentor and decreased funding, the patient instructor residency training programme is not active at this time.

Funding and structure

The university has picked up and funded some features of the programme that continue to be taught. Most of the education is now lecture-based with only a small component of patient interaction. The key feature of the initial programme was practice, followed by the feedback and instructions from patient educators. The new programme incorporates a summary of normal and abnormal factors in joint examination. This is in contrast to the more detailed introduction to teaching practical skills that was previously delivered. It is now run by orthopaedic surgery. Patient instructors are still involved but play a lesser role.

Programme evaluation

Evaluation of learners found:

– increased comfort with physical exam skills
– feedback from patients about both approach and exam skills improved physical exam skills
– better understanding of patients with arthritis.

Evaluation of patients found:

– increased awareness of health issues
– increased quality of life
– positive impact on patient's relationship with personal physician.

Some of the data from a previous evaluation with a multi-station objective structured clinical examination (OSCE) with standardised patients was never published because of the lack of funding. No long-term evaluations have been done.

Programme contact

Old programme: Maureen Gecht.

Current Initiative: see contact information in the article below.

Other initiatives and additional information

Patient Partners in Arthritis Program at the University of Toronto, Faculty of Medicine – see case study 4.2.

Outputs and resources

Gecht, MR. What happens to patients who teach? *Teaching and Learning in Medicine* 2000; 12 (4): 171-175.

Case study 4.4 – Parents' evaluations of medical students' paediatric interview skills, University of Adelaide, Australia

Description and history

This programme was developed in order to:

– obtain parents' evaluations of medical students' paediatric interview skills for feedback
– identify students at risk of poor performance in summative assessment.

It allows the Department of Paediatrics to meet university assessment policy requirements for early formative feedback. It also provides information about the clinical interview skills of a large number of medical students. Parent interview evaluations were superior to the existing formative mid-term clinical supervisor assessments in identifying weaker students.

Funding and structure

A few competitive grants were received from the University of Adelaide to support this project. Dr O'Keefe's involvement in the programme ended in 2005, but the initiative is still continuing. It is now self-sustained in the paediatric curriculum, requiring minimal running costs.

There is an introductory seminar at the beginning of the paediatric term (repeated several times a year) that focuses on background, introduction to the interview evaluation tool and an interview role playing activity. The main goals are to reduce student anxiety before the interaction and to introduce the evaluation tool. The students are then expected to obtain at least one parent evaluation. Participation is compulsory. Although students are provided with their score from the parent, the university keeps no record of it. Anonymised student scores are provided and students can compare their scores with their cohort and against a defined 'at-risk' score. Parents get no prior training or introduction and are recruited by the students. In this way students have control over which parents they ask to evaluate their interview skills, and which interviews are evaluated.

Programme evaluation

In the first year, 49 students were surveyed by anonymous questionnaire regarding the parent evaluation programme. There were 34 responses. Of those, 79% supported the programme and 68% reported no difficulty in participation. Students valued the opportunity to improve their skills in communication, knowledge and confidence, and to receive feedback regarding their interview skills. No long-term evaluations have been conducted.

Programme contact

Dr Maree O'Keefe, Associate Professor, Faculty of Health Sciences, University of Adelaide
maree.okeefe@adelaide.edu.au

Outputs and resources

O'Keefe M, Whitham J. Early identification of 'at-risk' students by the parents of paediatric patients. *Medical Education* 2005; 39: 958-965.

O'Keefe M, Sawyer M, Roberton D. Medical students taking the role of the mother in paediatric interview evaluation. *Medical Education* 2004; 38: 294-301.

O'Keefe M, Baghurst P, Sawyer M, Roberton D. The association between maternal ratings of child health interviews and maternal and child characteristics. *Family Practice* 2004; 21: 684-688.

O'Keefe M, Roberton D, Sawyer M, Baghurst P. Medical student interviewing: a randomised trial of patient-centredness and clinical competence. *Family Practice* 2003; 20: 213-219.

O'Keefe M. Should parents assess the interpersonal skills of doctors who treat their children? *Journal of Paediatrics and Child Health* 2001; 37: 531-538.

O'Keefe M, Sawyer M, Roberton D. Medical student interviewing skills and mother reported satisfaction and recall. *Medical Education* 2001; 35: 637-644.

Case study 4.5 – Operation House Call, Boston, USA

Description and history

Since July 1991, Boston University School of Medicine (BUSM), Department of Pediatrics, has been collaborating with the Arc of Greater Boston (ArcGB) in 'Operation House Call'. The programme is a required clinical educational experience for all third-year BUSM students. It was designed and implemented in response to parents' concerns at the ArcGB that physicians were not adequately trained to handle medical issues of children with disabilities. Dr Siegel, Director of Student Education in Paediatrics, in collaboration with ArcGB, organised and designed this educational initiative in which parents are teachers of third-year medical students through a home visit model.

Since its inception 16 years ago, approximately 2,300 students and 150 families have participated in the programme.

Funding and structure

Initial funding was received from the Department of Paediatrics and Arc of Greater Boston. The Department of Paediatrics pays for a programme coordinator who represents and recruits families (on a volunteer basis) for the programme. The coordinator gives an introduction at the beginning of the six-week paediatric rotation and a debriefing at the end. Students make a home visit to a family where the parents teach and evaluate the student. This programme is strongly supported by the university. The main principle is that patients are the best teachers. The initiative works well when students have experience with patients first and then go through a reflective process with faculty and patients.

Programme evaluation

Students have evaluated the programme (satisfaction surveys, focus groups and interviews), and reported an improvement in their knowledge, attitudes, sensitivity and understanding of children with disabilities and family dynamics. Parents' feedback (evaluation) goes into the academic record of the medical students. Evaluations have to feed into goals and objectives of the programme. A qualitative study was carried out to find out how parents felt about teaching and how students felt about being evaluated by parents. Data analysis had not been completed at the time of writing, but preliminary findings show that:

– some students forgot that they were being evaluated
– parents felt that they were in the best position to teach medical students.

A long-term evaluation has followed up medical students up to 20 years later. Data analysis for this study is also not yet complete, but general findings show that students who remembered the programme stated that it was an important experience.

They were struck how their family coped and how they had adapted to emotional and financial struggles. Students appreciated the home visit experience.

Programme contact

Contact at the Arc of Greater Boston: Anthony Sirignano, Director of Advocacy and Community Services, Arc of Greater Boston, Inc. Contact at Boston University School of Medicine, Department of Pediatrics: Dr Benjamin S Siegel.

Other initiatives and additional information

Dr Siegel also runs seminars called 'Humanism, Professionalism and Professional Development of Physicians'. At these, students come back and share their thoughts and feelings after patient interactions, followed by completion of a critical incident report. The initiative has spread to different departments and attendance is required.

The university also started implementing small group discussions with first-year medical students who meet patients and talk about their illness experience. At the end of the first year, students are assigned to doctors (a mentorship programme) and use standardised patient visits.

The American Academy of Communication and Health developed a video programme on communication skills led by Dr Denis Novak. This programme incorporates virtual patients that third-year medical students work with to develop case studies.

Outputs and resources

Operation House Call: Boston parents teach medical students about special needs children and their families. *Exceptional Parent Magazine*; 2002.

Voelker R. Putting mental retardation and mental illness on health professionals' radar screen. *Journal of the American Medical Association* 2002; 288 (4): 433-435.

Gosney Jr JE, Storman D, Geving M, Hui Liu L (2009 March 24). Operation House Call: A family-centered pediatric residency experience. *Clinical Pediatrics* online first; 2009.

Liu GC, Harris MA, Keyton SA, Frankel RM. Use of unstructured parent narratives to evaluate medical students competencies in communication and professionalism. *Ambulatory Pediatrics* 2007; 7: 207-213.

Siegel, B. Parent as teachers and evaluators of medical student professionalism. *Ambulatory Pediatrics* 2007; 7: 203-204.

Charon R. Narrative and medicine. *New England Journal of Medicine* 2004; 350 (9): 862-864.

Brach W, Pels R J, Lawrence RS, Arky R. Becoming a doctor: critical-incident report from third-year medical students. *New England Journal of Medicine* 1993; 329 (15): 1130-1132.

Case study 4.6 – Standardised patients as adjuncts for teaching pelvic examination, Graduate School of Nursing, University of Massachusetts, Worcester and Lowell, USA

Description and history

Pelvic examination is part of the mandatory course in the graduate nursing programme at the University of Massachusetts, Worcester. Dr Theroux's study explored graduate nurse practitioner students' perceptions of their experience when learning to perform pelvic examinations in the laboratory and subsequently performing them in clinical rotations.

One group was taught by faculty with voluntary peer examination, and the other two groups were taught by standardised patients (SPs). The university affiliated with the medical school had a standardised patient programme that was used for pelvic examination education in this initiative.

The programme ran for three years. In the first year, student volunteer peer examination was used. In the second and third years, standardised patients were used in pelvic (male and female) exam education.

The results of the study were shared with the Dean of Nursing. The recommendation was that this type of education should be incorporated into the student curriculum in nurse practitioner programmes.

Funding and structure

Initial funding was received from the Centre for Teaching and Learning at the University Massachusetts Lowell for studies that would improve teaching techniques. The funding was used to pay student fees for standardised patients in the study. The standardised patient programme at the University (Worcester campus) handled all the logistics of booking the patients and patient training for the second and third years of the study. At the present time the programme still continues at both locations of the university, with standardised patients used during pelvic exam education for graduate level nurse practitioner students. It is now a part of the Advanced Health Assessment course that is a requirement for all nurse practitioners across the country.

Programme evaluation

Twice during the three consecutive years, a survey was administered to students enrolled in the advanced health assessment course. It showed that those who were taught pelvic examination by standardised patients rated their learning experience more positively and reported a better understanding of exam techniques than students who learned by voluntary examination of classmates.

Genital exam is particularly stressful for students and being able to learn the skills from someone who is knowledgeable is very helpful and useful. Patients make students feel comfortable about this sensitive education area. No long-term evaluation has been done, but some positive feedback was received from a few students approximately one to two years after graduation.

Programme contact

Dr Rosemary Theroux, Associate Professor, Graduate School of Nursing, University of Massachusetts Worcester
rosemary.theroux@umassmed.edu

Other initiatives and additional information

Standardised patient involvement in Graduate School of Nursing at the University of Massachusetts is also expanding. They are involved in teaching second and third-year nurse practitioners through physical exams and problem visits. Feedback to students from patients is considered more helpful than that from faculty.

Outputs and resources

Theroux R, Pearce C. Graduate students' experience with standardised patients as adjuncts for teaching pelvic examinations. *Journal of the American Academy of Nurse Practitioners* 2006; 18: 429-435.

Case study 4.7 – Patients as Educators (PaE) Programme, University of Sheffield Medical School, UK

Description and history

The Patients as Educators (PaE) Programme at the University of Sheffield was launched in 2004. It was building on the enthusiasm of a small group of academics and simulated patients. It is now an established part of the undergraduate medical course.

The programme aims to:

– provide a high-quality learning experience, using the unrivalled knowledge of a patient's personal experience in dealing with their particular illness or complaint
– ensure that students have a broad understanding of the implications of illness and disease
– ensure that students appreciate variations in patients' experiences
– ensure that students can show appreciation of interprofessional management of disease from a patient's perspective.

Students meet with patients from the programme throughout the undergraduate medical programme. The volunteer patients use their own experiences to teach students about their medical conditions and about bedside manner, to discuss their illness and the impact it has had on them and their family. They may also assist in the assessment of students through the provision of informal feedback, and in formal examinations through the contribution of marks to a student's performance.

Funding and structure

The PaE programme was established with special funds (Professor Nigel Bax's National Teaching Fellowship grant), but now has core funding for a coordinator and an administrator, both full-time, with part-time secretarial support, reflecting institutional support. A steering group oversees the programme.

Over 700 patients are currently enrolled in the programme. People are recruited through personal contact, patient groups and networks in the community. Clinicians may also identify a patient attending a clinic who may be interested in getting involved. More recently, newly qualified doctors who have had the experience of working with the PaEs have recommended to their own patients that they get involved.

There is no formal payment other than travel costs. Volunteers receive a PaE lapel badge and certificate when they are enrolled, and there is a 'gold badge' in recognition of long service.

The most common reason people give for volunteering is the altruistic notion of wanting to give something back to the health service. There is generally very good communication and working relationships within the programme.

Patients are provided with a standardised induction and training session that includes a video demonstration of an OSCE, the process of history taking, teaching and giving constructive feedback, communicating with students, confidentiality, and health, safety and consent issues. If a patient is to be involved in a particular teaching session or assessment, more specific training is provided.

Programme evaluation

Feedback from volunteers and students has been consistently positive. Anecdotally, many volunteers have remarked that involvement has actually helped them communicate with health professionals and enable more informed decisions about their own healthcare.

Programme contact

Martin Hague, Coordinator of the Patients as Educators Programme.
m.g.hague@sheffield.ac.uk

Other initiatives and additional information

A neighbouring university that runs nursing and allied health professional educational programmes has shown interest in the programme. Links have also been made with the School of Dentistry where student dentists receive clinical teaching from a health professional that is then backed up by a simulated ward round for history taking. Future plans include introducing inter-professional learning with other faculties in the university.

For more information on the 'Patient as Educators' programme see the project website: www.shef.ac.uk/aume/pae_dept

Outputs and resources

Stark P, Hague M, Bax N. Involving patients as educators: adding value to clinical experience. *International Journal of Clinical Skills* 2009; 3: 64-69.

Level 5 – Patient teacher(s) as equal partners in student education, evaluation and curriculum development

Case study 5.1 – The Family Competency Project, Uniformed Services University of the Health Sciences (USUHS), USA

Description and history

The programme started in 1996, driven by personal interest and funding from the US Department of the Army and the Department of Defense (DoD). It initially involved parents of children with special needs as advisors and teachers in the DoD system of services for children with special healthcare needs.

At the request of a curriculum committee and with permission from the USUHS Institutional Review Board, 12 of these parents participated in a series of four focus groups to develop a list of desired competencies for medical students. The 203 discrete competencies included knowledge, attitudes and skills/abilities in the area of self-awareness, communication, medical decision making and advocacy.

Funding and structure

The medical education component started in 1999, with funding from the Josiah Macy Jr. Foundation and later the US Department of Health and Human Services. The aim was to build a patient-educator advisory board and hold a series of work groups to develop patient-centred medical education activities.

In 2007, a curriculum guide was produced and the medical school continued essential funding for the programme. The school funds salaries for two part-time coordinators (Home Visit & Patient and Family Coordinators) and honoraria for patient and parent advisors. There is very strong institutional support.

Activities that have been co-developed and co-taught by patient advisors and faculty integrate patient-centred activities while supporting learning objectives for the medical school, including:

- a home visit in the first year
- bioethics course in the second year that includes a session on decision making for very young children with serious health issues
- a session in a human behaviour course taught by a parent on family experience of development disorders
- a new health supervision curriculum in paediatrics in the third year that includes case discussions, observations in the clinic, and self directed reading
- a two-hour workshop co-taught with advisors and faculty in the third year on planning healthcare in the context of a patient's life.

Programme evaluation

Learner evaluation through journals, reflective writing and standardised patient encounters has shown improvement in:

- communication skills
- ability to describe the context of a patient's life
- ability to identify community resources for patients.

Long-term evaluations are planned as part of a current medical school curriculum reform effort.

Programme contact

Dr Janice Hanson.

Other initiatives and additional information

The medical school curriculum is now being reformed with a new curriculum scheduled for implementation from July 2011. One of the themes is integration of patient-centred activities.

A crucial aspect of sustainability for this kind of initiative is someone with tenacious commitment and personal interest to make it successful.

Outputs and resources

Randall VF, Hanson JL. The Family Competency Project. Uniformed Services University of the Health Sciences. *Academic Medicine* 2000; 75 (5): 529-530.

Hanson JL, Randall VF. Advancing a partnership: patients, families, and medical educators. *Teaching and Learning in Medicine* 2007; 19 (2): 191-197.

Hanson JL, Randall VF (2007) *Patients as Advisors: Enhancing Medical Education Curricula.* Bethesda, MD: Uniformed Services University of the Health Sciences; 2007. p.156.

Case study 5.2 – Integration of persons with HIV in problem-based tutorials, McMaster University, Ontario, Canada

Description and history

The programme started in 2001, initially funded by the Canadian Working Group on HIV and Rehabilitation as a research project. The initial focus was on inter-professional education and the programme involved two experienced patient educators. After the programme's evaluation it was surprising to find benefits to patient educators (not only for learners) and it was decided to look at this initiative from the perspective of patients' needs. Additional funding was received from the Canadian Working Group on HIV and Rehabilitation to focus specifically on evaluating patient educators. Patient educators were put through an extensive educational programme that equipped them to go beyond telling a story and to help facilitate the learning. The training programme has been developed and evaluated.

Funding and structure

On the basis of the evaluations, the Hamilton Aids Network took on the initiative and continues to run it to this day. They provide extensive training for patient educators and, as a result of their support, the programme has grown extensively and is now completely 'owned' by the community. Patient educators are compensated for their time.

Most faculties at McMaster are now actively involved in incorporating patient-educator initiatives into their curricula, although programmes have done this in different ways depending on curriculum needs. There is strong institutional support for standardised patients and simulation, and discussions about a centrally run programme specific to patient educators are underway.

Future goals and long-term impact evaluations are dependent on continuing government funding (related to the HIV patient educators). McMaster University is also developing a programme that involves other patients, not just HIV patients and is looking into facilitating a central programme for all patients as educators.

Programme evaluation

Broad themes that emerged from the data were related to benefits of involvement of persons with HIV-AIDS in the tutorial process. Four subthemes that emerged from this broad theme were:

– providing a perspective on the lived experience
– providing the context for learning
– challenging assumptions and values
– knowledge of resources.

Programme contact

Dr Patty Solomon, Professor & Director, PIPER, Faculty of Health Sciences, McMaster University.

Other initiatives and additional information

The goal (which differentiates this programme from many others) is not to own the programme, but have community run it. Programmes are grounded in problem-based learning. The university facilitates learning in small groups with specific tutor training sessions for faculty that are used the same way for patient educators. One of the challenges is to identify which patients are able to facilitate learning of students beyond just telling a story – not all are able to do this.

Outputs and resources

Solomon P, Salvatori P, Guenter D. Integration of persons with HIV in problem-based tutorial: a qualitative study. *Teaching and Learning in Medicine* 2003; 25 (4): 408-413.

Solomon P. People with HIV as educators of health professionals. *AIDS Patient Care and STDs* 2005; 19 (12): 840-847.

Solomon P, Salvatori P, Guenter D. An interprofessional problem-based learning course on rehabilitation issues in HIV. *Medical Teacher* 2003; 25 (4): 408-413.

Case study 5.3 – Production of learning materials about mental health, Open University, UK

Description and history

When the Open University made its first exploration into mental health education in the early 1990s, the initiative was taken to involve users in the design of what was to be a multidisciplinary, multi-professional course. It aimed to offer students the opportunity to include the perspectives of users and survivors in their learning. Users contributed in different ways: providing material for audio-cassette recordings, writing personal accounts, contributing to or commenting on draft teaching materials.

The experience of involvement was published as a paper, co-authored by one of the academic course team, and a survivor, acting as consultant to the team. An anthology of personal narratives about mental distress and its consequences was eventually published as a course reader (*Speaking our minds. An anthology* – see below). The module was replaced in 2004 with a new course having significant involvement of service users. The most recent course (K225: Diverse perspectives on mental health) also has considerable user involvement. A new reader (*Mental Health Still Matters*) was published in 2009.

Funding and structure

The original course received Department of Health funding, with core institutional support from the start.

Programme evaluation

The paper in social work education reflects on the problems and challenges of involving users/survivors, specifically in the context of education about mental health and illness, but with generic messages. Among the issues raised were:

– language and terminology
– diversity of perspectives of both users and professionals
– tensions inherent in collaboration (for example, the survivor co-author did not want survivor accounts juxtaposed with professional stories)
– questions of power and stigma
– the potentially stressful effects of involvement for both the users and the academic staff.

It also emphasised that an important part of learning for all involved is the process itself. Feedback about the reader has been 'unremittingly enthusiastic'.

Programme contact

Jill Reynolds. j.c.reynolds@open.ac.uk

Other initiatives and additional information

The Practice-Based Professional Learning (PBPL) Centre for Excellence in Teaching and Learning website: www.open.ac.uk/pbpl that states:

'The PBPL is about developing expertise and knowledge around practice-based professional learning and offering this to all Open University colleagues and other bodies with an interest in practice-based learning.'

Several Open University staff members were seconded to the University of Birmingham Centre for Excellence in Interdisciplinary Mental Health.

The aim was to investigate different approaches to the teaching of practitioners with specific regard to mental health teaching. The project is described at: www.open.ac.uk/pbpl/activities/details/detail.php?itemId=49c0e5bb7280f&themeId=49887a1373845

Outputs and resources

Reynolds J, Read J. Opening minds: user involvement in the production of learning materials on mental health and distress. *Social Work Education* 1999; 18 (4): 417-431.

Read J, Reynolds J (eds). *Speaking our minds. An anthology.* Basingstoke: Macmillan Press Ltd; 1996. (ISBN 0333678508) Described as: 'This is an exciting collection of writings by people who have experienced mental distress. It includes accounts of psychiatric treatment, psychotherapy and alternative treatments; life in mental institutions and moves into the community; self-help methods and work to improve mental health services. Moving, sometimes funny and often dramatic, the pieces are written by some of the key activists in the mental health survivors' movement, as well as by people best known as writers and poets and others who, for a period of time, have been caught up with mental distress and have something original to say.' (www.palgrave.com/products/title.aspx?PID=254591)

Reynolds J, et al. (eds). *Mental Health Still Matters.* London: Palgrave Macmillan; 2009. (ISBN 9780230577299) Described as: 'In a collection of more than 50 readings, Mental Health Still Matters reflects the wide diversity of views about how best to understand and explain mental health and distress. Drawing on writings from a range of academic sources, as well as the rich and compelling stories of mental health service users themselves, it provides a sharp challenge to traditional understandings of mental illness and aims to illuminate future thinking, policy and practice.' (www.palgrave.com/products/title.aspx?PID=318130)

Additional resources at: www.open.ac.uk/pbpl/activities/details/detail.php?itemId=49c0e5bb7280f&themeId=49887a1373845

Case study 5.4 – Participation in Nurse Education (PINE), School of Nursing, Midwifery and Physiotherapy, University of Nottingham, UK

Description and history

The aim of the PINE initiative is to promote mental health service user involvement across the School of Nursing, Midwifery and Physiotherapy. The group was built on the foundation of a three-year collaborative participatory action research project. The project was conducted by staff in the school and a local training and research organisation (Making Waves) whose members have experienced mental distress. Academic staff and service users had been meeting for several years before funding was identified for the project (see below). It was decided from the outset that, since users and carers, although they were often grouped together, were not a homogenous group and often had very different agendas, the project focused initially on service users. A steering group equally represented by academics and users met regularly. The concept of involvement was felt to perpetuate power imbalances and a model of participation was adopted instead.

Through community networks, 16 people with experience were recruited. They met over several months and identified four educational themes around which to develop teaching materials. These themes were:

– professionals on tap, not on top
– strategies for survival
– diagnose this – see the person not the label
– living on an acute ward.

Two-hour, themed teaching sessions were designed by the group. The term 'facilitator' was the preferred term for the users in their educational role.

Training was provided and the sessions piloted, during which attention was given to the support needs of the service user facilitators. The facilitators work in pairs, and prefer to attend the sessions without a member of staff.

The School of Nursing itself has a Service User and Carer Advisory Group that has been meeting regularly since 2005 to discuss various ways that people with experience can be involved with the school. Outputs from the group include policies and guidelines about such issues as fees and expenses, how to involve people with teaching or speaking to students, how they might be involved in recruitment of students, and responding to consultative documents.

Funding and structure

PINE was established with funding from the University's Learning and Teaching Development Fund. A service user worker is now employed half-time in collaboration with a local organisation called Self Help Nottingham. The initiative has had the full support and encouragement of the school.

The terms of reference are to:

– develop a strategy for mental health service user involvement in the school
– map and monitor service user activity within curricula across diploma, degree and post-graduate programmes
– develop links with groups in the community
– identify and develop the potential for user involvement
– ensure that recommendations from PINE are appropriately represented in the relevant school groups
– publish examples of good practice in user involvement on the school website (see below)
– disseminate the work nationally and internationally.

Programme evaluation

Evaluation was carried out as a component of the participatory action research.

A small service user sub-group undertook focus groups and interviews with students before, and towards the end of the programme, and with some of the facilitators. Students and facilitators also completed questionnaires at the end of each session. A number of themes emerged.

The experience was largely positive for all involved, students and facilitators alike. Some students had negative views beforehand but none were evident afterwards.

One of the original academic team (Brenda Rush) also focused her PhD research on the initiative. Her thesis, 'Mental health service user involvement in the education of student nurses: a catalyst for transformative learning', found that students benefitted from being taught by service users and, providing certain mechanisms were in place, could be transformed by their experience in terms of positive changes in attitudes and practice.

Programme contact

Theo Stickley, Associate Professor of Mental Health. theo.stickley@nottingham.ac.uk

Brenda Rush, Associate Professor of Mental Health. Brenda.rush@nottingham.ac.uk

Joan Cook, User Involvement Development Worker, Self Help, Nottingham. joan@selfhelp.org.uk

Information about Making Waves can be found at: www.makingwaves.org

Other initiatives and additional information

A pilot project has also been conducted (Service User Student Assessment, SUSA) to explore involvement of service users in assessing students in practice (see Stickley et al., 2010).

Outputs and resources

PINE details and terms of reference are found on the School of Nursing website: www.nottingham.ac.uk/nursing/usercarer/pine.php

See also the Service User and Carer website at: www.nottingham.ac.uk/nursing/about/usercarer/index.php

Rush B. Mental health service user involvement in nurse education: A catalyst for transformative learning. *Journal of Mental Health* 2008; 17 (5): 531–542.

Rush B. Mental health service user involvement in England: lessons from history. *Journal of Psychiatric and Mental Health Nursing* 2004; 11 (3): 313-318.

Roberts S, Collier R, Shaw B, Cook J. 'Making waves in nurse education: the PINE project'. In: Stickley T and Bassett T (eds.) *Teaching Mental Health*. Chichester, John Wiley and Sons; 2007.

Stickley T, Rush B, Shaw R, Smith A, Collier R, Cook J, Shaw T, Gow D, Felton A, Roberts R. Participation in nurse education: the PINE project. *Journal of Mental Health Training, Education and Practice* 2009; 4 (1): 11-18.

Stickley T, Stacey G, Pollock K, Smith A, Betinis J, Fairbank S. The practice assessment of student nurses by people who use mental health services. *Nurse Education Today* 2010; 30 (1): 20-25.

Case study 5.5 – Service user and carer involvement in the School of Health Community and Education Studies, Northumbria University, UK

Description and history

A service user group was established at Northumbria University in the context of social care education. This was in response to the recommendations of the Department of Health (Department of Health, 2002). The experience was described and discussed in a paper by Molyneux and Irvine (2004, see below). It was felt that authentic involvement should not be confined to one programme and demanded a whole-school approach.

A strengths, weaknesses, opportunities, threats (SWOT) analysis identified opportunities for increasing networks and inter-professional working, as well as potential threats such as duplication of effort. Involvement is now established throughout the school.

Service users and carers are involved in a range of curricular activities including student recruitment, developing teaching materials, assessing students and programme evaluation, and revalidation.

Funding and structure

The initiative has had full institutional support from the start. A Service User and Carer Subcommittee was established reporting to the School Learning and Teaching Committee. Recent changes have seen committee meetings reduced with time released devoted to half-day workshop discussions of key topic areas. For example, how to involve service users in student education and feedback in the practice setting. A new role of service user champion within programme/discipline areas carries a 50 hour/year workload commitment.

Programme evaluation

No formal overall evaluation has been undertaken. Evaluation at an academic programme level has been positive and has been shared widely by staff in conference presentations and by publication (Jones et al., 2009, see below)

Programme contact

Jeanie Molyneux, Chair of Service User and Carer Sub-Committee.
jeanie.molyneux@northumbria.ac.uk

Other initiatives and additional information

One of the workstreams of the Centre for Excellence in Teaching and Learning for Healthcare Professional Education in the North East of England (CETL4HealthNE), a collaboration between higher education institutions, including Northumbria University, and the NHS, was 'People with Experience – User Involvement'.

This workstream created a narrative archive of first hand accounts of users' experience of health and social care in the North East (www.cetl4healthne.ac.uk/view).

Another resource created is a DVD about living with sensory impairments, developed in collaboration between people with sensory impairment and Shoot Your Mouth (a NE-based media company working with people with disabilities). These resources are available for educators to incorporate into their teaching.

Outputs and resources

Molyneux J, Irvine J. Service user and carer involvement in social work training: a long and winding road? *Social Work Education* 2004; 23: 293-308.

Morgan A, Jones A. Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: a literature review. *Medical Teacher* 2009; 31 (2): 82-95.

Jones D et al. Service user and carer involvement in physiotherapy practice, education and research: getting involved for a change. *New Zealand Journal of Physiotherapy* 2009; 37(1): 26-32.

Level 6 – Patients involved at institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development

Case study 6.1 – Comensus, University of Central Lancaster (UCLan), UK

Description and history

Comensus is a faculty-wide initiative to involve service users and carers in the education of health and social care professionals in a systematic and comprehensive way across all schools and departments in the Faculty of Health at the University of Central Lancashire (UCLan).

The project built on a foundation of work already undertaken by an informal network/multidisciplinary group interested in user involvement and has involved participatory action research.

The goals of the project were to support user and carer involvement in all aspects of the Faculty's work: teaching and learning, research and strategic decision making; and to foster effective links and mutual support between the university and various community groups with a stake in health and social care. It benefitted at the start from a clear standpoint of support from the Dean of Faculty and a significant level of institutional funding. There was also a senior manager given responsibility for faculty user and carer involvement. This assisted with the navigation of bureaucratic hurdles and committees and aided reporting directly to the Faculty Executive Team.

The project has been championed from its inception by the project coordinator and a number of key academic allies. They have faced various cultural impediments (staff resistance of various sorts), but also saw staff member's willingness to embrace and support the idea of user participation. Practical issues of staff time, capacity and resource played a part. Some 'quasi-cultural' issues, such as how university work is organised and decision making undertaken, reduced over time, rather than being transformed wholesale. To date the project has managed to insinuate service user and carer inputs into most of the courses in the faculty although there are still areas of resistance.

Future goals are to:

– continue with the original mission
– target those areas of provision/schools which are less engaged with Comensus at present
– bid for and secure external funding to contribute to running costs
– make inroads into other parts of the university beyond the Faculty of Health
– build on and strengthen community engagement activity so that the university has a more reciprocal role in its community.

Funding and structure

Faculty initially provided £300K for three years from 2004 to 2007. The project has subsequently negotiated rolling annual funding. The core staffing posts, a full-time coordinator and an administrator, were made substantive in 2009. There is a core group of service users and carers, the Community Involvement Team, (CIT), who meet as the strategic committee of the project. Authority for decision making in the project is vested in this group. There are also extensive links with nearly 200 community members and local groups, who also have input into the university.

Course leaders, module leaders or other academics make specific requests for involvement that are fielded by the CIT. Involvement opportunities (teaching, research or strategy) are filled with recourse to community members as necessary and relevant to particular individuals' interests and experiences. Involvement opportunities are also proactively sought by attending relevant university committees and planning meetings.

Interesting issues of identity between service users, academics and students have arisen in the course of this project. The Comensus members have begun to occupy academic social space and the inevitable forging of relationships and friendships have subtly altered how people are seen and see themselves.

For many staff and students, the idea of service users teaching in classrooms is now taken for granted. For others, progress has been slower, but the trend appears to be progressive. Completely user-led modules (planning, development of materials, course management, teaching, and student assessment all in the hands of a team of service users) have been developed. A notable example of this is for the BA Social Work course. There is interest in service users:

– relating their personal experiences to specific learning objectives at course, module or single teaching session levels
– contributing beyond the singularly personal and addressing broader concepts and issues relevant to a service user movement.

Programme evaluation

Comensus was established as a participatory action research project. Early findings have been published and there is a commitment to continuing to do so. Given the research design, this is more process-orientated than impact evaluation. Audit data are collected for all student contacts. The project has also become involved in various small scale evaluations of discrete elements of work, for example, developing e-learning resource and internet-based peer-support.

Programme contact

Lisa Malihi-Shoja: LMalihi-shoja@uclan.ac.uk
Mick McKeown: MMckeown@uclan.ac.uk
Soo Downe: sdowne@uclan.ac.uk

Outputs and resources

Downe S., McKeown M, Johnson E, Comensus Community Involvement Team, Comensus Advisory Group, Koloczek L, Grunwald A, Malihi-Shoja L. The UCLan Community Engagement and Service User Support (Comensus) project: valuing authenticity, making space for emergence. *Health Expectations* 2007; 10: 392-406.

Hopkins R, Cox P, McKeown, M. Making sense of health and social care service user participation in a university setting: the relevance of social movement theory: proceedings of Alternative Futures and Popular Protest, 12th International Social Movements Conference April 2-4 2007, Manchester; 2007. [CD-Rom]

McKeown M, Malihi-Shoja L, Downe S, Supporting The Comensus Writing Collective. *Service user and carer involvement in education for health and social care*. Oxford: Wiley-Blackwell; 2010.

Comensus website has additional info and some videos of participants: www.uclan.ac.uk/health/about_health/health_comensus.php

Two international conferences were convened in 2007 and 2009 (Authenticity to Action).

The work presented at these conferences illustrated the diversity of user and carer involvement initiatives.

Case study 6.2 – Community involvement in undergraduate medical course, Leeds Medical School, UK

Description and history

This programme reflects the underlying philosophy of a social contract between Leeds School of Medicine and the local community. It illustrates the expectation that medical graduates will be culturally competent and appreciate the benefits of working collaboratively with the voluntary sector. Medical students in the programme have a range of opportunities for involvement with the local community. The aim is to broaden their appreciation of important social, cultural and psychological dimensions of health and ill-health. They are encouraged to adopt a holistic approach that encourages them to think more widely than the medical model.

Year 1 – Patient visit

Early in the course, pairs of students meet a volunteer patient, usually in the patient's home. They learn about physical, psychological and social aspects, and how to effectively communicate with the person to identify these. Students also visit a community group or healthcare setting. They reflect on these visits, which are as diverse as possible to reflect the local population, by creating and presenting a digital story. Over 2,500 students have undertaken this since its inception.

Year 2 – Engaging with people

External experts from the community are invited to the medical school to run interactive sessions. Sessions are on themes such as poverty, gender, culture, domestic violence and alternative medicine. Over 80 external experts and 30 outside organisations have contributed to the programme.

Year 2 – Valuing diversity

A number of voluntary sector organisations and health professionals run interactive sessions. Students select two out of three workshops from a choice that includes ethnicity, the social model of disability, deaf awareness, sexuality, and mental health and discrimination.

Year 2 and 3 – Community-based activities

Second and third-year students have the chance to choose a two-week community-based Student Selected Component (SSC). During this component they spend time with a voluntary or statutory sector organisation, including local primary schools. A selection of the reports are written up in the community newsletter. Students may also choose to undertake a community-based SSC in their third year.

Funding and structure

A full-time post of Community Education Development Officer was established in 1998. Their role is to identify and develop learning opportunities and maintain links with the community. This has been achieved through regular meetings and a community newsletter. The latter is issued approximately three times a year, circulated to over 500 community contacts and key people in the medical school. It is also a useful medium through which community organisations can learn about the student's and each other's activities. In 2006, a fortnightly community blog began, maintained by the officer, with contributions from anyone involved with the programme, including students.

Initial funding was boosted by national award (BUPA Communication Award, £10K), but it is now core funded.

Programme evaluation

Feedback is sought from all stakeholders after each round, but evaluation is short term. Generally feedback is excellent. Some students have carried out research for local organisations.

Programme contacts

Barry Ewart, Community Education Development Officer, and Dr John Sandars, Senior Lecturer, Medical Education Unit, School of Medicine, University of Leeds. UK: b.r.ewart@leeds.ac.uk and j.e.sandars@leeds.ac.uk

Other initiatives and additional information

The Patient Voice Team, led by Penny Morris, sees people from patient and carer groups joining clinical teachers and educators in devising roles for medical student teaching and assessment, also scenarios for inter-professional learning. Significant adjustments to original clinician-authored briefs have resulted from this collaboration. Patients and carers have also trained as simulated patients and facilitators and become co-teachers.

There are also links with Leeds Dental School and colleagues in the School of Health Care. See: www.medicine.leeds.ac.uk/medstaff/person. aspx?personID=4

Outputs and resources

Ewart B, Sandars J. Community involvement in undergraduate medical education. *Clinical Teacher* 2006; 3: 148-153.

Ewart B, Sandars J. A community blog for medical students and the wider community. *Clinical Teacher* 2009; 6: 110-112.

Morris P, O'Neill F. Preparing for patient-centred practice: developing the patient voice in health professional learning: proceedings of Beyond Reflective Practice, 3 July 2006. Leeds; 2006. www.leeds.ac.uk/medicine/meu/lifelong06/ papers/P_PennyMorris_FionaO'Neill.pdf (accessed March 2010).

Details of community involvement in Leeds MBChB course: www.leeds.ac.uk/medicine/ mbchb/community.html

Community Newsletter and Community Podcasts: www.leeds.ac.uk/medicine/meu/community.html

Community Blogspot: http://communityppd. blogspot.com

Case study 6.3 – School of Health, University of Northampton, UK

Description and history

The course development team of a new pre-registration programme at the University of Northampton worked with the local health authority to involve patient groups in course design. A user reference group was created in 2001, with membership drawn from a wide spectrum of patient and voluntary sector groups. The members' experience and expertise proved invaluable in shaping the course, particularly on issues such as encouraging a partnership approach. Members also commented on draft documentation in advance of validation of the course.

In 2005 the user group evolved into a strategic group. Its remit now encompasses curriculum delivery, selection of students and staff, student assessment and being part of the educational review process with outside agencies. Members' narratives of their 'lived experience' are still being used to inform workshops for both practitioners and academics about how best to engage and involve patients in the training process, the outcome of which was a set of ground rules. Some of their stories were eventually captured in a book (*Look at me and smile*, see below). Published in 2009, it is given to all health and social care undergraduate students at the start of their course and used in teaching sessions with postgraduate health and social care practitioners.

Funding and structure

The initiative had strong institutional support and received core funding from the beginning, with input to most of the programmes run by the School of Health.

The strategic group has 20 members/participants and meets three times a year for a whole day. Members' expenses are reimbursed (including carers). Members are recruited through local media and patient councils of local trusts. They serve for three years. They are also reimbursed for face-to-face teaching in the classroom and offered opportunities to access educational seminars/ programmes that are of interest to them.

Programme evaluation

Response to patient involvement in curriculum design and delivery from patients, students and staff has been very positive, despite some initial anxieties.

Programme contact

Dr Sue Allen, Dean of School of Health. sue.allen@northampton.ac.uk

Other initiatives and additional information

Members of the strategic group have also been involved in projects, seminars and reviewing research ethics proposals in the Centre for Health and Wellbeing Research at the University of Northampton. See: www.northampton.ac.uk/chwr

Outputs and resources

Ingham M. How patients can contribute to nurses' education. *Nursing Times* 2001; 97: 42-43.

Allen S, Lilley L (eds.). *Look at Me and Smile*. Northampton: Stenhouse; 2009. (ISBN 9781906398040) This is an innovative resource developed by Dr Sue Allen, Dean, and Linda Lilley, Senior Lecturer, in the School of Health. Of the book, co-editor Sue Allen said:

'As the School of Health has a fundamental role in preparing and supporting people to work with patients, service users, carers and the public, we felt it was only right that these people should be involved in as many aspects of the process of preparing health and social care practitioners as possible. We are very grateful to them for sharing their stories.'

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Case study 6.4 – University User Teaching and Research Action Partnership (UNTRAP), University of Warwick, UK

Description and history

UNTRAP was set up at the Institute of Health in the School of Health and Social Studies at the University of Warwick in 2004. It is a mechanism to support and involve users and carers in the region in teaching and research in health and social care. It is primarily concerned with the fields of medicine and social work. Guiding principles of UNTRAP are that members should be:

– valued as full members of any working group and not merely as 'service user/patient experience' specialists
– provided with adequate support, including access to information and IT facilities and opportunities for training
– paid and reimbursed at a fair rate for any activities they undertake.

There is both individual membership as well as organisational membership. This involves completing a membership form to receive mailings on opportunities for participation, and notices of training and other events. The membership currently includes more than 130 individuals and over 20 organisations.

In education, UNTRAP members take part in admissions for social work and medicine, in face-to-face teaching, leading or facilitating seminars or giving lectures, the development of audio-visual material, assessment of work, and curriculum review and planning through membership of committees and stakeholder groups.

In research, members sit on research advisory groups, research funding committees, are involved in the preparation of research proposals, and in research governance.

Funding and structure

UNTRAP was established through a mapping exercise of individuals who had been involved informally in teaching and of local voluntary sector organisations who were invited to a consultative open day with the opportunity of signing up. The funds for this event came from Warwick Medical School.

Subsequently two tranches of funding have been obtained from the Higher Education Infrastructure Fund to support development of UNTRAP.

Another source is the money given by the General Social Care Council (GSCC) to each social work course, both qualifying and post qualifying, to develop user involvement in curriculum planning, admissions, teaching, assessment and governance. These funds support a coordinator one day a week. There is also an administrator in the Institute of Health who maintains the database. Two senior academics give 20 days a year between them to UNTRAP to work with members in developing strategy, funding and activities. The funds also provide payment to members involved in meetings and committees.

There is a steering group whose membership consists of between two and three academic staff and six and eight members of UNTRAP. Initially for the first five years, this group met every six weeks. With the expansion of activities, three sub-groups (teaching, research and recruitment) were set up. These groups report on their activities to the steering group when it meets once a term. This allows for broader involvement of members. Training and support is given to members. Diversity in relation to age, ethnicity, educational background, and health status is important and links with organisations as well as individuals ensure this. Recently, young people have been recruited for involvement in the social work teaching and assessment.

Programme evaluation

No formal evaluation of UNTRAP has been carried out. However, both the GMC and the GSCC have commended the mechanism and practices of UNTRAP in supporting and facilitating user and carer involvement in teaching when validating training in social work and medicine at the University of Warwick.

Programme Contact

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Outputs and Resources

Guidelines have been developed on payment (through negotiation with the university), for those requesting user or carer involvement from UNTRAP, and for members themselves. See: www2.warwick.ac.uk/fac/cross_fac/ healthatwarwick/untrap

Blaxter L, Hundt G, Jackson A. AMEE 2006: Strengthening user voices in the medical curriculum. Proceedings of the Association for Medical Education in Europe Annual Meeting, September 14-18 2006. Genoa; 2006. See: www.amee.org/documents/AMEE%202006%20 Abstracts.pdf

6.3 Summary

The 24 case studies provide a series of snapshots of activity from both sides of the Atlantic and beyond. They are across all levels of involvement, health and social care professions (albeit mostly medical, since that is the source of most of the literature), and both pre and post qualification and CPD (although mostly undergraduate, again, reflecting the literature).

A wide range of methods and settings in which people are involved are described: story-telling and writing; visits to their homes; instructing, assessing and giving feedback to and about students in the classroom and the workplace; using drama or video; mentoring.

We cannot claim that this is a representative picture of all activity since the sampling frame comprised respondents to a survey based on reports published in the academic literature. However, from our knowledge of that literature, and our own activity and networks, we are confident that they give an overview of some important issues. These will be dealt with in Section 8: Discussion and conclusions.

7 Survey of current activity in UK medical and dental schools

As stated in Section 2: Methods, a web-based questionnaire was sent to all the nominated primary contacts (NPCs) of the HEA Subject Centre in UK medical and dental schools with a covering email. Respondents were asked to rate activity in their own institution against the 'Ladder of Involvement' (Tew et al., 2004), and comments invited. The survey was launched twice, in January 2010 then again in March, with reminders.

7.1 Results

There were 50 subject centre NPCs in medicine and dentistry. Of these 12 replied to the first survey, and, at the time of writing this report, 20 to the second, totalling 32 in all (64% response rate).

Level of involvement

Some 22 of the 32 indicated the level of involvement of their institution, as shown in the table below.

Table 3: Level of involvement of institution

Level of involvement	Number of respondents
1	5
2	8
3	9
4	1
5	0

A wide range of ways in which patients/users are involved were detailed. These included involvement in teaching (topic areas including motherhood, alcoholism, deafness, visual impairment, and rheumatological conditions) and also course planning, delivery and assessment.

Specific areas included community orientation, 'the cancer journey', intimate examinations, expert patients, and student selection.

Plans for developing involvement

Of the 32, 22 responded to this question, which asked whether there were plans to develop involvement in any of the following areas:

– direct delivery of teaching
– curriculum/module planning
– programme management
– recruitment and selection of students
– practice-based learning
– student assessment
– course evaluation.

The majority replied positively. See table 4.

Table 4: plans to develop patient involvement

Plans	Number of respondents
Yes	17
No	5

Of the 22 respondents, 21 answered the question 'How much priority is given at the moment in developing user involvement in the curriculum?' as shown in table 5.

Table 5: priority for developing user involvement

Priority	Number of respondents
A great deal	2
Moderate	8
Low	11
None	0

Despite the majority of respondents viewing development as a low or moderate priority, development is occurring in a range of areas, as is illustrated by these respondent quotes:

'Module leads are being encouraged to engage with patient organisations to achieve this.'

'We have just recruited patients to all key curriculum committees.'

'This is an aspirational issue and engaged with when opportunities present.'

'Patients as educators programme formally are being developed – volunteer patients, expenses paid, database set up...'

'This is being discussed with other universities on an inter-professional basis.'

Challenges and problems

Respondents were asked what challenges or problems they had encountered in involving users. Issues raised are illustrated in the following selected quotes.

Clarity about purpose

'For some areas it is hard to involve service users and be clear what they might do and how they might contribute. But for other areas it is much more straightforward.'

Questions and concerns about motives and representation

'What is a lay person? And what have they to gain from doing the curriculum stuff?'

'Identifying people without a 'single issue' outlook.'

'We feel it is important that the individuals involved should be representative of the broad range of patients and not individuals with personal axes to grind.'

Organisational and practical issues

'Issues of data protection (in terms of liaising with NHS partners) have influenced how we are progressing. It is not a deterrent, but makes the process more complex.'

'You need to be very flexible to allow for sickness etc, and draw from a pool of potential patients.'

'Coordinating times and needs of users with curriculum needs.'

'The first challenge is to find the time and people resource to consider it. Then find the evidence, be informed of how to do it well, and develop it.'

7.2 Summary

The survey provides a thumbnail sketch of activity in a selection of undergraduate medical and dental schools in the UK. For technical reasons, although some respondents gave their contact details, it was not possible to identify non-responders to increase response rates. The picture is therefore incomplete.

Nonetheless, it gives an impression that is corroborated by the literature and our own experience, that user involvement in medical and dental undergraduate education is patchy.

There are areas of innovation and good practice, and an intention, if of relatively low priority, to develop matters. Issues highlighted in the survey will be picked up in Section 8: Discussion and conclusions.

8 Discussion and conclusions

This report's research (literature reviews, 24 case studies and the telephone interviews from which they were compiled, and the survey) provide a international snapshot of the current 'state of the art' of patient/user involvement in educating health and social care professionals. Predominantly observations have been at pre-registration, undergraduate levels. The main conclusions to be drawn from these data and the various policy and guidance documents referred to earlier are discussed below.

8.1 The diverse landscape

Patient/user involvement in health professional education is widespread. It is characterised by great diversity of levels of involvement and approaches, and, we surmise, of underlying value systems.

The most comprehensive initiatives have largely arisen in the context of education for social care and non-psychiatric mental health, with nursing moving in the same direction. These developments are still relatively recent and driven by UK government policy on user involvement. Medicine and dentistry have not developed patient/user involvement to anywhere near the same extent. Most of the reported initiatives are single educational experiences for a specific group of learners, often isolated examples within the broader curriculum.

Few examples of active involvement to any extent were found in postgraduate training or continuing professional development. There are intentions to develop them, but they tend to be afforded relatively low priority. Somewhat paradoxically, most of the published literature, both descriptive and empirical, comes from medical education.

8.2 Policy and institutionalisation

The UK is the world leader in the formalisation of patient/user involvement at an institutional level. Much of the literature and the case studies in which patients/users are involved in educational activity beyond the teaching role are from the UK. This institutional support has been driven and supported by government policy and some funding. For example, there is a statutory requirement of social care education programmes that users are involved in curricula, and that a small amount of funding is provided (by the General Social Care Council). This ensures that such programmes achieve high levels of involvement. These external drivers for patient/user involvement are not seen elsewhere in the world, nor are they strong drivers in medical education.

In the UK, the General Medical Council's latest recommendations on undergraduate education, Tomorrow's Doctors 2009 (GMC 2009), only mentioned patient involvement in vague terms. For example, seeking patients' views about teaching, as part of the data that should inform quality assurance. At the time of writing, supplementary guidance is being drawn up that will expand on and clarify some of these issues.

Recent documents on the future of medical education from North America similarly make few references to patient (community) involvement.

8.3 Outcomes

It is impossible to make definitive statements about best practice, or what does or does not work, by looking at the outcomes of patient involvement. This is either because initiatives are not comparable or because they have failed to be adequately studied and described.

The underlying reasons for patient/user involvement in health professional education are varied. So too are the educational objectives (if defined) and methods, making comparison between examples difficult.

There is very little evidence of the impact of patient/user involvement in health professional education in terms of long-term outcomes, specifically changes in behaviour and in the health professional practice. There is good evidence of short-term benefits to students and the patients/users involved, especially at the level of satisfaction and reaction (Kirkpatrick, 1996). Very few serious concerns have been documented.

If all educators are to embrace patient involvement, and if institutions are to provide support and funding, especially in times of economic constraint, there will need to be evidence of the value added to the educational programmes.

This is especially true in the case of medical education, where external policy drivers are weak and educational innovation is becoming more evidence-based.

8.4 Institutional support, funding and sustainability

Most initiatives require a champion to lead their implementation. More often than not this has been catalysed by special funding of one kind or another: grants internal and external to the institution, including research grants, foundation funds, prizes and endowments, and in the case of patient educators in arthritis, the pharmaceutical industry. This start-up funding has provided the opportunity to demonstrate the worth of patient involvement and to attract core institutional funding. Loss of external funding, in the absence of subsidy from the host, contributed to the contraction or even demise of programmes. Institutional support has also been essential for sustaining initiatives, whether in terms of their place in the curriculum, for continuing funding or for expansion.

8.5 Infrastructure

Each institution needs to establish an infrastructure and appropriate policies to support patient/user involvement in education. Policies and processes are required to address issues such as recruitment, payments, contracts, and ethical issues, as well as providing a safe, comfortable and welcoming environment for patients/users. Mechanisms for systematically gathering feedback from patients/users about their involvement should be developed, notwithstanding the challenges. Training and support in these new ways of working should also be provided, for both patients/users and faculty. There is usually the need for a coordinator who can be the link between the academic institution and the patients/users.

8.6 Meaningful involvement and partnership

A clear vision with well-articulated goals, flexibility and choice, underpinned by supportive systems and culture is needed:

'to ensure that the involvement of service users, carers, patients and the wider public is so embedded that it feels like "it's the way things are done" rather than an obligation.'

(Trent SHA, 2005)

It is important to pay attention to language (including use of technical jargon) and to strive to ensure diversity is reflected and minority views represented. It is also evident that when users are involved at a significant level in an institution, challenges may arise around status, power and relationships. These can be resolved, but changing or at least influencing institutional culture presents a significant challenge. We still have a lot to learn about how academic institutions can develop meaningful partnerships with patients/users for the purpose of health professional education.

8.7 Research

In the light of the variable quality of much of the evaluation and research in this area, a substantial research agenda needs to be developed. Much of the current literature is descriptive and lacks rigour. Not only have outcomes not been studied, but the educational theory underpinning patient involvement is lacking. Towle et al. (2010) identified some of the questions demanding further inquiry:

– What are the drivers of patient/user involvement?
– What are strengths and weaknesses of different approaches, and how do these vary between professions and disciplines, and between countries and across cultures?
– What factors influence what works, and why?

– How do structural and organisational factors, such as location, access and safety, influence development of programmes?
– What factors influence patients' experiences of involvement?
– What are the key outcomes, short and long term (especially the latter), for all parties?
– What factors influence sustainability of programmes?

8.8 Knowledge translation

In the absence of evidence it appears that there are many possible approaches to developing and embedding involvement in institutions and training programmes, and no one 'right way'. There is a need for flexibility in adopting and adapting particular models to ensure they are appropriate to the setting. There is also a need to learn from and build on experience, to avoid reinventing the wheel, and to connect those working in the field.

There is currently no mechanism for easily finding out who is doing what, how and with what results, or to bring together educators in different health professions. A repository of examples of good practice, including a database of initiatives and materials would be helpful to academic communities.

9 Recommendations

Generally, with some notable exceptions that are highlighted in the case studies, patient/user involvement in most areas of health professional education, not least medical education, is patchy. It depends upon the energy and enterprise of local enthusiasts and the acquisition of funds and fortuitous circumstances. It is not high on the agenda of influential leaders of health professional education, either at the institutional or national level. We believe a high level forum is needed to tackle the specific issues raised in this report.

We recommend holding a series of meetings bringing together leaders and thinkers from academic institutions, professional bodies, the healthcare system, the lay community and other stakeholders interested in health professional education.

We recommend that the initial discussions of this group be focused on the following objectives:

– To develop and articulate a shared understanding of the relevance and importance of patient/user involvement in health professional education.
– To make explicit the connection between patient/user involvement in the education and training of future health professionals and priority healthcare issues, such as patient safety, quality of care, patient-centred care, shared decision making and so on.
– To raise the profile of patient/user involvement in health professional education: at various levels in the educational system, including national policy and standards documents, and within individual institutions, especially in those professions where it is not, or barely, on the agenda.

A central repository of good practice including a database of innovations and materials to facilitate knowledge transfer would be extremely useful for all stakeholders (academics, practitioners and organisations involved in support and advocacy of people in the community). There is also a need to facilitate development of involvement, for example, through conferences and workshops.

We also make the call for more research to further develop the evidence base. This needs to go beyond the common descriptive studies that describe 'what we did', with a fairly low level and short-term evaluation. These are needed to inform the community about innovations and disseminate interesting ideas, but longer-term research is needed. This should be research that:

– addresses effects on practitioner behaviour, health outcomes and the factors influencing sustainability
– identifies best practice, addressing questions such as 'why does this work here, and not there?'.

This is what has been called 'clarification' research (Dornan et al., 2008), and it should be a priority. Such long-term research requires a programme of funding.

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Appendices

Appendix 1. Phone interview consent letter

THE UNIVERSITY OF BRITISH COLUMBIA

Division of Health Care Communication
informed and shared decision making

#400 - 2194 Health Sciences Mall
Vancouver, B.C. Canada V6T 1Z3

Phone Interview Consent Letter

Title: Patient and Carer Involvement in Health Professional Education. Report to the Health Foundation on the 'State of the Art'.

Principal Investigators: Professor John Spencer, Director of Research and Development, School of Medical Education Development, Newcastle University, UK

Co-Investigators: Dr. Angela Towle & Dr. William Godolphin, Co-Directors, Division of Health Care Communication, College of Health Disciplines, University of British Columbia.

Funding: This study is funded by the Health Foundation (UK).

Purpose: The aim is to describe 'state of the art' scholarship and practice in active involvement of patients in health professional education (at all levels: undergraduate, postgraduate and continuing professional development) and to identify gaps in both research and practice. It will cover the following areas:

- Background and context
- Comprehensive review and summary of literature
- Database of key people/units/networks involved in research and development in both the UK and internationally
- Case studies to illustrate leading practice from UK and internationally
- Gap analysis to inform discussion of challenges, research and policy agenda, and implications for practice
- List of resources

Study Procedure: We are asking you to participate in a scheduled telephone interview. The interview will be recorded. We will ask for your verbal consent to participate in the interview and your verbal consent to have your interview recorded in the beginning of the interview. You may ask to stop the recorder at any time. It will take 30 minutes or less and focus on these questions:

1. Who funded the programme?
2. What is the main focus and goal of the programme?
3. What are future goals for the programme?
4. How does the institution and organizational culture support the programme?
5. Is this programme part of the core curriculum?
6. Please tell us of publications, links to resources and key contacts for the programme.

7. What are similar programmes elsewhere that you know of?
8. What features of your programme make it different from others?
9. Have you done any long-term impact evaluation of the programme?

Report Deadline is March 12, 2010 with interviews scheduled until March 9th at the latest.

Confidentiality: Information gathered from this survey will **NOT** be confidential. Your responses may be part of our report to the Health Foundation. We will send you a draft case study based on information from the telephone interview and ask you to confirm or correct the information.

Risks: Some programmes in this study may be sufficiently unique that anonymity cannot be assured. We will not link any information to individuals by name in any published reports. If there is value in publishing negative information (e.g., to identify barriers to programme sustainability) we will try present it in ways that do not link directly to specific programmes or people. However, it may be possible to surmise which programme the information is about or who provided the information. In some cases, summarized data may be linked to programmes, by citation of publications about the programme, e.g., to identify exemplary programmes as models for others who want to develop similar initiatives.

Benefits: You may or may not benefit from participation in this study. Some benefits may include raising the profile of successful initiatives, increased literature citations and potential collaboration for future research studies.

Contact: If you have questions or want further information you may contact Nataliya Karpenko at 604-822-8002 or email isdm@interchange.ubc.ca. If you have any concerns about your treatment or rights as a research participant you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598.

Consent: Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to your professional standing. If you participate in the phone interview, it is assumed that you consent to participate in the study.

Sincerely,

Professor John Spencer, Newcastle University

Dr. Angela Towle, Dr. Bill Godolphin and Nataliya Karpenko, University of British Columbia

Appendix 2: The Cambridge Framework[1]

This framework comprises a set of attributes of educational settings, for the most part independent of their physical location, seen predominantly from the patient's perspective, which could be manipulated to shape the experience for all parties. The list was drawn from the collective experience of the authors which embraced a wide range of clinical disciplines, in both hospital and the community, and the basic sciences (but note, there were no patients/users in the group). The list is not exhaustive.

The attributes were grouped under the headings: Who? How? What? and Where?, to aid description. The potential value of the framework is that it provides an overview, and offers curriculum planners and teachers possibilities to reflect on how active a role patients/users are playing and what they are teaching students in any particular educational encounter. In theory it could thus be used to monitor whether there is enough variation in the involvement of patients/users in a course, or part of a course.

It could also be applied to any learning situation involving patients, including paper-based simulations.

Who?

Each patient is an individual. Since most people belong to more than one cultural group, and outward manifestations of their background may, in any case, be misleading, it is important to respond to each patient as an individual, acknowledging the cultural context in which health and illness are expressed, and being sensitive to stereotyping and prejudice. The list of relevant individual characteristics might include age, gender, ethnic background, socio-economic status and sexual orientation. For the curriculum as a whole, it is important that students encounter as wide and representative a societal sample as possible.

How?

This group of attributes can be modified in line with intended learning outcomes, as the full range of all may arise during normal clinical interactions. Some (such as 'novice' or 'expert' patient) can only be altered by involving different patients, but most apply to all patients. To illustrate the use of the model in evaluating a clinical teaching session, consider the 'Questioning – Informing' domain. A patient with diabetes might be prepared for student contact by being asked to describe what it is like to have the condition. The student may also be 'primed' to learn from the patient about the experience of having diabetes – in this instance the patient is 'informer'. Likewise, the same patient may be briefed to ask the student questions about their problem, to gain a deeper understanding. The student will thus have to be prepared to give information to the patient and to research any areas of uncertainty or ignorance; they could then send an explanatory letter to both the patient and the clinical teacher – here the patient is 'questioner'. The implications would be different in each of these situations if the patient was a 'novice', i.e. recently diagnosed, or an 'expert', with long standing diabetes. A full list of the 'How?' attributes is shown in the box.

How?

- Brief contact – Prolonged contact
- Passive role – Active role
- Time limited – Time committed
- Trained – Untrained
- Inexperienced ('novice') – Experienced ('expert')

- Planned encounter – Unplanned encounter
- Simulated situation – Real situation
- 'Questioning' – 'Informing'
- Known patient – Unknown patient
- Focussed learning – Holistic learning
- Tutor involved – Tutor not involved

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1 Spencer et al. Patient-oriented learning: a review of the role of the patient in the education of medical students. Medical Education 2000; 34: 851-857.

What?

This aspect of the interaction between patient, student and clinical teacher looks at 'content'. It describes the sort of problem the patient might present to the student. A patient with a serious fracture of the ankle being involved in teaching at different points in their illness (awaiting X-ray results shortly after injury; waiting to go to theatre; during the operation; recovering in hospital; attending their general practitioner because unable to work; or attending for removal of the plaster). A patient in the early stages of an illness will be able to help the student understand their anxieties and fears in a different way from a patient with a long established problem who may have been given adequate and effective explanations and appropriately counselled. Likewise, patients who meet students on several occasions over a period of time, whether in hospital or in the community, will have opportunities to be involved in student learning that are not possible when there is a single encounter. A patient who is in the throes of illness will obviously tell a different story from one who is well. It is important for students to hear about both aspects. The subject of learning may be quite different at these different stages and the patient may be better placed to be involved in learning in very different ways. The 'What?' attributes are listed in the box.

What?

- Undifferentiated problem – Defined problem
- Straightforward – Challenging
- High impact – Low impact
- General – Specific
- Clinical science – Basic science

- Minor – Major
- Simple skills – Complex skills
- 'Revealed' attitudes – 'Hidden' attitudes
- Particular focus – Generic approach

Where?

Finally, where the interaction takes place will also influence roles, both that of the patient in student learning and that of the student in patient care. Seeing a patient in their own home (the patient fully dressed and speaking their own language) will have a different impact on the student's learning compared to seeing the patient in a high dependency unit, lying virtually naked, no family members present, speaking in a language they have difficulty understanding. These two scenarios offer different learning opportunities (and obviously vastly different levels of patient/user involvement). A list of the 'Where?' attributes are shown in the box.

Where?

- 'Our place' – 'Your place'
- Community – Hospital
- 'My culture' – 'Your culture'

- 'My clothes' – 'Your clothes'
- Service setting – Educational setting

The framework has not been validated

Appendix 3: The Ladder of Involvement

This framework was published in 2004 in a 'good practice guide' written by Jerry Tew, Colin Gell and Simon Foster on behalf of the Mental Health in Higher Education project, National Institute for Mental Health in England and Trent Workforce Development Confederation.[2] It was based on field research on service user involvement and drew on a range of materials and literature. It provides 'pointers towards good practice in relation to each of the components of effective involvement' and offered a range of evaluation tolls, of which the Ladder of Involvement was one.

Level 1: no involvement

The curriculum is planned, delivered and managed with no consultation or involvement of service users or carers.

Level 2: limited involvement

Outreach and liaison with local service user and carer groups. Service users/carers invited to 'tell their story' in a designated slot, and/or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offeredfor their time. No opportunity to participate in shaping the course as a whole.

Level 3: growing involvement

Service users/carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecturer rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users/carers are not represented. Some support available to contributors before and after sessions, but no consistent programme of training and supervision offered. No discrimination against service users and carers accessing programmes as students.

Level 4: collaboration

Service users/carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. This is underpinned by a statement of values and aspirations. Payment for teaching activities at normal visiting lecturer rates. Service users/carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users/carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.

Level 5: partnership

Service users, carers and teaching staff work together systematically and strategically across all areas – and this is underpinned by an explicit statement of partnership values. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long-term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users and carers to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

2 Tew J, Gell C, Foster S. Learning from experience. Involving service users and carers in mental health education and training. Nottingham: Higher Education Academy/National Institute for Mental Health in England/Trent Workforce Development Confederation; 2004.

Appendix 4: Spectrum of Involvement

Appendix patient educators: Role and degree of engagement classification

Patient Role	Degree of engagement with role (1)	Degree of engagement with role (5)
1. Paper-based or Electronic Case/Scenario: Patient is focus of a paper-based, electronic or web-based case/scenario.	Case/scenario written by someone other than the patient(s) and no input from patient(s) other than serving as the example/subject	Case/scenario written and evaluated by members of patient group being described.
2. Standardised/Simulated Patient: Patient encounter with student is scripted, serves as an example to illustrate or reinforce learning (e.g. teacher asks patient to provide student with history or student practice a clinical exam)	Individual who is not a patient with the specific condition reading or acting out a pre-prepared script which was not written or evaluated by patient(s)	Individual with the condition simulating a clinical encounter with students using a script written and evaluated by members of that patient group
3. Patient Shares their Experience with Students within Faculty-directed Curriculum: Patient is invited to share experience. Faculty plan the encounter but patient determines personal comfort and level of participation.	Single contact in which patient(s) share their experience in their own words but students do not have an opportunity for engagement (such as asking questions).	Multiple interactive encounters between patient(s) and students in which students have the opportunity to ask questions
4. Patient Teacher(s) involved in Teaching and/or Evaluating Students: Patient given preparation for specific teaching role, may actively question students, be involved in giving feedback and/or evaluating their performance.	Patient educator(s) given minimal preparation for a single encounter with students in which they are given independence to teach, question and/or evaluate students.	Multiple encounters between students and patient educator(s) in which the patient is given extensive preparation for teaching role and works collaboratively with faculty as equal partner in teaching and/or evaluation.
5. Patient Teacher(s) as Equal Partners in Student Education, Evaluation and Curriculum Development: Patient involved in many aspects of educational delivery, development and evaluation, beyond specific courses to curriculum as a whole. A true partnership in which patient(s) make meaningful and valued contributions to decision making.	Patient teacher(s)' involvement across all aspects of education: teaching, evaluation and contributing to curriculum; however, their involvement in these aspects may be sporadic and/or their contribution to some roles may be greater than others.	Complete immersion of patient teacher(s) in all aspects of education: teaching, evaluation and curriculum design with this involvement being sustained over time and a substantial input to all three roles.
6. Patient(s) Involved at the Institutional Level in addition to Sustained Involvement as Patient Teacher(s) in Education, Evaluation and Curriculum Development for Students: As above but there also are institutional policies that ensure involvement in decision making bodies within undergraduate, graduate and continuing health professional education.	Patient teacher(s) involved in all aspects of education delivery: teaching, evaluation and curriculum design as well as some type of institutional support for patient involvement in education.	Patient teacher(s) involved in all aspects of education delivery: teaching, evaluation and curriculum design as well as an institutional directive for patient involvement in education and extensive involvement of patient teacher(s) on boards at the institutional level.

Degree of engagement with role: 1 2 3 4 5

Appendix 5: Useful resources

Networks

Developers of User Carer Involvement (DUCIE) is a network that aims to enhance the involvement of users and carers in learning and teaching, through development of a support network for user and carer involvement development workers employed within UK higher education institutions (HEIs): www.mhhe.heacademy.ac.uk/networks/ducie

Professional Education Public Involvement UK PEPIN at: http://pepin-uk.net

Other web resources

The Social Work Education Participation website, developed by an alliance of the Social Care Institute for Excellence (SCIE), Shaping Our Lives, the University of Sussex and a steering group of service users and carers at: www.socialworkeducation.org.uk

It aims 'to share good practice around the participation of service users and carers in social work education'.

Database of literature

University of British Columbia, Division of Healthcare Communication: Patient Involvement in Health Professional Education – A Bibliography 1975-2009 at: www.chd.ubc.ca/dhcc/node/67

Narrative archives

Healthtalkonline, award-winning website of the DIPEx charity where people can share in others' experiences of health and illness, watch or listen to videos of the interviews, read about people's experiences and find reliable information about conditions, treatment choices and support: www.healthtalkonline.org

People With Experience is one of the workstreams of the Centre for Excellence in Teaching and Learning in the NE of England, CETL4HealthNE. The group has recorded the experiences of users of a variety of services, from which a repository of archives is being developed for use by healthcare educators in the North East to link with modules and other learning materials and to encourage future healthcare providers to routinely include the views of patients and other service users, in order to ensure quality, patient-centred, healthcare provision at: www.cetl4healthne.ac.uk/view/workgroups/people_with_ experience/projects-and-activities/narrative-archive-1/narrative-archive

The Patient Voices Programme (winner of BMJ award for Excellence in Healthcare Education, 2010) is at: www.patientvoices.org.uk

It was founded in 2003 and 'aims to facilitate the telling and the hearing of some of the unwritten and unspoken stories of ordinary people so that those who devise and implement strategy in health and social care, as well as the professionals and clinicians directly involved in care, may carry out their duties in a more informed and compassionate manner'.

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