I’m unique; not merely a diagnosis. Don’t assume! Take time to listen, understand & give options. I hope you’ll guide me on my journey.

Reproduced from a Tweet from a group of interprofessional students and mentor with a chronic condition, in a Health Mentors Program summarizing their key message as a group for a symposium to share their learning. With kind permission from Diane Desjardins (patient teacher), Milena Semproni, Jennifer Lukomskyj, Amy Le, and Lindsey McCloy (students)
Patient involvement in medical education

Introduction

Patients have always been involved in medical education but too often in the past they have been used as convenient and passive tools for learning and practice. The first major review of the contribution that patients can make in the education of medical students, beyond their traditional role as ‘clinical material’ and teaching aids, was by Spencer et al. (2000). Since then, several reviews have explored both theoretical and practical aspects of patient involvement (Wykurz and Kelly 2002; Repper and Breeze 2007; Morgan and Jones 2009; Jha et al. 2009a; Towle et al. 2010; Spencer et al. 2011). We have assembled a comprehensive bibliography comprising over 400 papers published in English between 1970 and 2011 covering healthcare professional education (Towle and Godolphin 2012).

The focus of this chapter is the active involvement of patients, a term we use to describe the involvement of people who are engaged in teaching, assessment or curriculum development because of their expertise or experiences of health, illness or disability and who are aware that they have designated teaching roles. We exclude involvement of people who role-play patients to express symptoms, conditions or life stories they do not actually have (simulated patients). We include examples of standardized patients where they are being themselves (such as women who teach intimate examinations), though we admit this is a grey area. We exclude examples of patient stories (narratives) considered as learning resources; we also exclude indirect assessment of learning through anonymized feedback forms. Finally, we exclude informal learning in clinical settings where the patient’s role is still essentially passive and their priority is to receive care.

Active patient involvement occurs throughout the continuum from undergraduate education, postgraduate education, continuing professional development (CPD), and in-service training, although the majority of reported initiatives occur in undergraduate courses or in postgraduate training of mental health professionals. In theory, patients can contribute to many different aspects of the educational process, including direct delivery of teaching and learning, curriculum and course planning, programme management, recruitment and selection of students, student assessment, and course evaluation (Tew et al. 2004). In medical education, patients are mainly involved in curriculum delivery and, to a much lesser extent, curriculum development and student assessment (Jha et al. 2009a); few other roles are currently represented. A greater range of patient involvement is found in nursing and social work education (Repper and Breeze 2007).
The earliest examples of active patient involvement in teaching are interventions in which the patient was an instructor of clinical skills. The longest-lasting programmes are those in which patient instructors teach intimate examinations or musculoskeletal examination (Towle et al. 2010). Over the last two decades, professional educators have made use of the expertise of patients in order to enrich the education of students in a variety of ways, providing learning experiences that could not otherwise occur and broadening 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 medical schools only focus on one patient population or a limited selection. Typically, one or more patients are invited into the classroom or a small group tutorial to tell their stories and answer questions from students. The range includes people with human immunodeficiency virus (HIV) infection, cancer, disability and mental illness, and caregivers (Anderson et al. 2011; Wittenberg-Lyles et al. 2011). Patients may co-tutor sessions with faculty (Solomon et al. 2005). Home or family attachment schemes permit students to interact with patients over a period of time to learn about a variety of conditions in the wider community context (Shapiro et al. 2009). The aim may be to promote humanism and patient-centred care (Kumagai 2008), or foster more positive student attitudes towards certain stigmatized or underserved groups. Examples include workshops run by professional actors with learning disabilities or teaching by parents of children with chronic illness (e.g. Hall and Hollins 1996; Blaylock 2000). Community-based programmes include senior mentor programmes in which students are partnered with an elderly person who is ‘ageing well’ (Stewart and Alford 2006), health mentor programmes in which interprofessional groups of students learn from someone with a chronic condition (Collins et al. 2011), and placements in which students or residents learn from people living in deprived inner city areas and workers in the agencies that provide them with services (Anderson and Lennox 2009; Sturm et al. 2011). Patient organizations may contribute to, or lead, CPD activities on specialized topics such as fetal alcohol syndrome and there may be public members on committees that plan CPD (British Medical Association 2008).

In this chapter we explain why it is helpful to involve patients as active partners in education; we describe examples of some of the most well developed patient-as-teacher approaches, and examine the evidence that involving patients can improve outcomes. We conclude by giving a practical guide to involving patients.
Language: words, meanings, terminology

We use the term patient, for the sake of brevity, to include people with health problems (service user, client, or consumer), their caregivers (including carers, parents, and families), and healthy people (community member, citizen, or lay person). We chose to use ‘patient’ as our umbrella term—it being the most commonly recognized word; however, the language of ‘patient involvement’ is confusing and controversial.

Language not only transmits values and beliefs, but also reflects existing power relations. The use of the word patient is emotive, because in many people’s minds it is associated with passivity, the sick role and disempowerment. As such it sits oddly with recent rhetoric about the importance of patient empowerment and activated patients. In the UK the term user or service user has increasingly replaced patient in relation to involvement in health and social care service delivery. However, in other parts of the world, including North America, ‘user’ is associated with illicit drug use. Even in the UK there are those who consider the term service user as passive and not inclusive of those who cannot or do not access services (McLaughlin 2009), or as implying provision of a technical service rather than holistic, relationship-centred care.

In some health professions, client is the preferred term—and preferred relationship. But there are also ‘consumers’, ‘mental consumers’, ‘people with...’ [a condition, disability], such as ‘people with HIV infection’, ‘survivors’, ‘activists’, ‘people in recovery’, ‘experts by experience’, and so on. The words people use to think of themselves in relation to the healthcare system vary according to the practitioner they are consulting, their condition and the stage of their illness, and can therefore have personal and emotional significance (Speed 2006). For example, some people who have battled with cancer or mental illness regard themselves as survivors, and this is how they prefer to be known, leading to a proliferation of literature on survivorship. The lack of agreed terminology is important for educators for several reasons. Strong emotions generated by language and labels create barriers to communication and partnerships. Whichever discourse we use identifies a power dimension and hierarchy of control (McLaughlin 2009) and is descriptive not of a person but of a relationship. Each of these words carries different meaning and none is acceptable by everyone as an alternative to patient. The inevitable multiplicity of terms complicates scholarly activity: it makes searching the literature difficult, and writing and talking about the topic cumbersome.

Furthermore, not all patients involved in health professional education are ill or are currently receiving care. There are many well people who
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have perspectives or experiences of value to health professional learning. These include older people, caregivers of people with chronic illness or disability, parents of normal children, people from specific ethnic groups, refugees, people who are marginalized or disadvantaged (for example the homeless or recent immigrants). The term ‘lay’ may be more inclusive but it defines people in terms of what they are not (a professional) and implies a lack of expertise and in our experience is universally disliked even by people who cannot agree on any other term. Other terms found are ‘citizens’, ‘community members’ and ‘the public’, but these do not clearly differentiate health professionals from non-professionals.

Complications of terminology extend to the many names used for patients actively involved in medical or other health professions education. For example, patients may be teachers, educators, instructors, teaching associates, professional patients, mentors, partners or consultants. Many patient involvement initiatives have coined their own local terminology and the meaning of terms is not always consistent. This makes literature searches difficult and may be one reason why reviews of the literature using similar but not identical inclusion criteria miss many relevant papers.

Classification schemes

The diversity of educational initiatives in which patients are involved requires a classification scheme. Without such a framework there is no agreed way that authors can characterize the role of patients in their initiatives, making scholarly communication difficult. It is often difficult to find out from published work exactly what the patient’s role was in the educational programme described, especially the degree to which patients were actively involved, whether their role was explicitly identified as teacher and the degree to which they participated in decision making. For example, 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, whereas in other cases their role is to be interviewed. The expected learning outcomes would be quite different for those different roles. Several schemes have been developed to classify the variables so that initiatives can be consistently described and compared, for example with respect to outcomes. They can also be used to track changes over time to answer questions about how and why the role or degree of involvement changes.

The Cambridge Framework (Spencer et al. 2000) was developed to facilitate discussion about involvement of patients in clinical education. It
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is based on four sets of attributes of situations and environments in which 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 educational content, including type of problem (general versus specific) and the knowledge, skills and values to be learned.

**Where**: location of interaction, e.g. community, hospital ward, clinic.

The Cambridge Framework is a tool that could be used by curriculum planners and educators to review and monitor the extent to which patients are actively involved. It has not been validated.

A different approach to classification is based on the degree of engagement, from minimal involvement to full partnership. Tew et al. (2004) described a ‘Ladder of Involvement’ in curricular development and delivery ranging from Level 1 ‘No involvement’ to Level 5 ‘Partnership’. Their tool, developed in the context of mental health education and training, can be applied to other educational programmes and across the educational continuum.

**Level 1: Little involvement**—curriculum is planned and delivered with no consultation or involvement.

**Level 2: Emerging involvement**—outreach and liaison with local user and carer groups; they are invited to tell their story and are occasionally consulted in relation to planning, but have no opportunity for shaping as a whole.

**Level 3: Growing involvement**—users and carers contribute regularly in more than one aspect of education and training. They are reimbursed and there is some support. Key decisions on education may be made in forums, in which users or carers are excluded.

**Level 4: Collaboration**—users and carers may contribute to key discussions and decisions; the value of this is acknowledged by all concerned. A coordinated programme of involvement and support is developing.

**Level 5: Partnership**—all partner groups work together systematically and strategically, underpinned by explicit statement of partnership values. All key decisions are made jointly. Infrastructure is funded and in place for support and training.

We have developed and field-tested a taxonomy with elements of both these models that identifies six main educational roles and for each role
identifies six attributes associated with the degree of involvement (Spencer et al. 2011).

**Rationale for involvement of patients in medical education**

There are many reasons for patient involvement in health professional education, which differ by profession, country, and over time (fig. 27.1). In general, decisions to involve patients have originated from socio-cultural change and associated policy responses. We discuss three clusters of reasons that are not mutually exclusive but are each rooted in a different discourse. It is important to recognize that, at the time of writing, the movement to involve patients actively in the education of health professionals is based more on the power of these rationales than on educational theory or robust evidence of beneficial educational or health outcomes.

![Figure 27.1](image)

**Figure 27.1**
Reasons for patient involvement in health professional education.

**Public and patient involvement in healthcare: government and professional policy directives**

The importance of public and patient involvement in healthcare is recognized in many countries. Members of the public are frequently consulted about services, policy and research as part of a growing consumerist model of healthcare. In the UK, government policy has placed the public and individual patients at the centre of healthcare over the past 20 years and successive policy documents have emphasized a patient-led service based on choice, participation, and partnership. Within this context the UK government has recently made clear its expectations that service users and carers should be involved in the education and training of health professionals, a policy directive that has been taken up by accrediting bodies. Although medical education lags behind nursing and social work in its requirements for extensive patient–public involvement, the General Medical Council does require data on the
quality of medical education programmes to include feedback from patients. The most significant activity has been in the field of mental health; originally in mental health nursing, extended more recently to social work, psychiatry, and clinical psychology. These policy directives have resulted in a large number of initiatives such that the UK leads in institutionalizing patient involvement in education.

Irrespective of national government policy, however, almost all health professions espouse a version of patient-centred care in their good practice model, which involves patients in decision-making, with a focus on individual people’s preferences, life circumstances, and experience of illness. There is at least a conceptual link between patient involvement in education, patient involvement in care, and improved health outcomes. However, patient-centredness is typically framed as a set of values and virtues learned from doctors as role models, reinforced through structured educational input from medical educators, and, paradoxically, not from patients (Bleakley and Bligh 2008).

**Social accountability of higher education institutions: the moral imperative**

Universities and medical schools are being increasingly scrutinized with regard to the gap between societal needs and the educational system (Towle and Godolphin 2011a). Community engagement initiatives signal recognition by academic institutions that they need to respond effectively to society’s evolving health needs. Involving patients in medical education is one way to bring the voice of the community into the medical school. Initiatives such as community-based service learning, especially in the USA, come from the moral imperative to address health disparities. Although active patient or community involvement are not in themselves prerequisites for service learning activities, people in the community play a variety of roles along the spectrum of involvement from passive recipients of care (the classic provider–patient relationship), to facilitators of reflection seminars, mentors, and assessors of students. The provision of opportunities for service learning has recently been adopted as an accreditation standard for North American medical schools. However, there remains a wide gap between service or outreach and collaborative partnerships with the community, leading to the integration of community members into academic medicine as mentors and teachers (Hunt et al. 2011). Other patient involvement initiatives in the USA (e.g. the senior mentor programmes) have their origin in the need to improve healthcare for the underserved.
The expert patient: enrichment of education

Patients bring a diversity of expertise to their teaching role (Wykurz and Kelly 2002). The recognition of patients as experts comes in part from the concept of encounters between professionals and patients as ‘meetings of experts’, first elaborated by Tuckett et al. (1985). Health professionals bring biomedical expertise and patients bring expertise of their personal and cultural background and their experience of living with illness or disability. Broadening curricula to include the psychosocial is especially necessary when educating professionals to deal with the increasing burden of chronic disease, where patient and family are the chief providers of care and where day-to-day management involves much more than attention to biomedical concerns (Towle and Godolphin 2011b). In some disciplines, the expertise of patients has been used to augment a scarce pool of clinical teachers or to create safe learning environments in which students can practise clinical skills.

Theoretical perspectives

The impetus for patient involvement has largely come from social change and policy directives. Not much of the literature about patient involvement in education is informed by learning theory. Patients as educators challenge the nature of expertise and power, yet so far there has been a failure to explore social issues surrounding patient involvement such as how students learn with rather than just about patients (Rees et al. 2007). Such learning not only implies a greater level of activity on the part of patients but also reflects the dynamic mutuality that occurs between students and patients. An example of the kind of work that would advance understanding of learning from patients is the study by Henriksen and Ringsted (2011) who interviewed occupational therapy and physical therapy students about their experience of learning from patient instructors with arthritis (in the absence of faculty); in this context the added value derived from the combination of content matter, pedagogical format and patient–student power relations. The content matter was complemented by the provision of realism and individual perspectives on rheumatism; the pedagogical format was authentic and intimate in the style of instruction and feedback; and the patient instructor-student relationship was characterized by balanced power relations that supported the legitimacy of learning and allowed mistakes and questions (Henriksen and Ringsted 2011).

Socio-cultural learning theory in which learning is conceptualized as participation in a social process provides a useful way to contrast learning with patients to the usual concept of individual knowledge acquisition. Learning by participation also appears to be consistent with
the ways in which community-based organizations conceptualize learning as compared to faculty in higher education (Bacon 2002): for example, faculty identify themselves as ‘knowers’ and ‘individuals’; community members identify themselves as ‘learners’ and ‘collective’. Theories such as situated learning (Lave and Wenger 1991) offer insights into issues such as power relationships, identity, roles and discourse that are pertinent to considerations about patient or user involvement. The work of Katz et al. (2000) provides an example of how a sociocultural perspective can be used to explore how students learn with rather than simply about patients in the context of a conversational forum that permits appreciation of the different points of view that participants bring to bear on an ethical dilemma. Rees et al. (2007) used sociocultural learning theory to show that both students and patients are legitimate peripheral participants in the community of medical practice, and generated recommendations that would lead to active collaboration between qualified health professionals and patients. They hypothesized that, as a consequence, a new level of knowledge ‘production’ rather than ‘reproduction’ may emerge within the medical education community.

Similarly, Bleakley and Bligh (2008) propose a theoretical model of collaborative knowledge production 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 task shifts from that of knowledge transfer to genuine facilitation, and the process of education becomes a ‘mutually beneficial dialogue supported by experts’.

Another area ripe for theoretical exploration is that of patient expertise within the context of health professional education, i.e. what knowledge can patients contribute? Theories of development of professional expertise and the literature on the expert patient or lay expertise are difficult to apply in this context. Exploration of patient expertise is located within the broader theoretical debate about the status of medical and scientific expertise in late modern society and the value and distinctiveness of ordinary people’s knowledge, and whether these are two distinctly different types of knowledge or a continuum (McClean and Shaw 2005). The most relevant analysis we have found is in relation to the added value of patient participation in biomedical research by Caron-Flinterman et al. (2005). They use the term ‘experiential knowledge’ to refer to the ultimate source of patient-specific knowledge, the often implicit lived experiences of individual patients with their bodies and their illnesses as well as with care and cure. It arises when these experiences are converted, consciously or unconsciously, into personal insight that helps someone to manage their condition. Experiential
expertise arises when patients share this knowledge so that the communal body of knowledge exceeds the boundaries of individual experiences. The theories of expertise and the validity of knowledge outlined by Caron-Flinterman et al. (2005) are as applicable to education as to research and have important implications. For example, they may determine criteria for selection of patient educators (stage of development of experiential knowledge; extent to which patients have shared experiences with peer groups) and attitudes of faculty towards patients as educators (perceptions about the validity of their knowledge).

Examples of patient involvement in medical education

We give four examples that illustrate a range of ways in which patients have been involved as teachers. We chose these because there is a unifying theme that permits different initiatives to be clustered together and some conclusions to be drawn: patients as teachers of clinical skills; senior mentor programmes; involvement of people with mental health problems; and parents as teachers (see fig. 27.2). Other examples can be found in reviews by Wykurz and Kelly (2002), Repper and Breeze (2007), Morgan and Jones (2009), Jha et al. (2009a), Towle et al. (2010), Spencer et al. (2011), and Towle and Godolphin (2012).

Figure 27.2
Examples of patient involvement in medical education.

Patients as teachers of clinical skills
There is cross-over between standardized patients (SPs), simulated patients, and patients who teach clinical and communication skills. We deal here only with cases where patients are being themselves, teaching on their own bodies and using their own lived experiences (although they may have been trained to teach in a standardized way).

Physical examination skills

Patient Instructor (PI) programmes, in which patients teach physical examination and communication skills, were developed in the early 1970s as a response by professional educators to perceived problems with the teaching of basic clinical skills by clinicians, notably that students were rarely observed or given feedback on their performance (Towle et al. 2010). Early studies provided evidence of acceptability, short-term effectiveness and cost efficiency. PIs provided a safe learning environment in which students felt less pressure to perform because of the reduced power differential between student and patient compared with student and clinician. The first programmes used PIs who were themselves (either normal or with defined signs and symptoms); however, by the late 1970s Barrows and colleagues had developed sophisticated simulation techniques, the foundation for the wide and varied use of SPs today (Wallace 1997). The PI concept went into decline apart from female and male intimate examinations and musculoskeletal examinations, although it has witnessed a renaissance in recent years, in part because of its perceived cost effectiveness (teaching basic physical examination skills is expensive).

Intimate examinations

Intimate examinations include pelvic, breast, testicular and rectal examinations, although most examples in the literature describe patients teaching the female examination. The first Gynecology Teaching Associate (GTA) programme in the late 1960s was inspired by Barrows’ early work (Kretzschmar 1978). By the early 1980s the use of GTAs had become widespread in North American medical schools; male TAs were introduced to teach the genitorectal examination, but these programmes did not become as well established. The Netherlands, Sweden, Belgium, Australia, and the UK have adopted GTA programmes more recently. Reasons for the success and longevity of the programmes include the anxiety faced by students in learning these skills, and the inherent difficulty in teaching and assessing intimate examinations in an ethical manner, although the fact that students continue to report learning on unconsenting anaesthetized women suggests that patients are still inappropriately used as teaching material (Rees and Monrouxe 2011). The objectives of GTA programmes may include not only technical and
communication skills, but attitudes towards women and women’s health issues, including well-women checks and contraception. Another common objective is to reduce anxiety for students and patients. In general, students report high satisfaction with the experience: learning is non-stressful and they receive immediate and constructive feedback on their performance; improvements in clinical skills have been convincingly demonstrated (Jha et al. 2010).

Musculoskeletal examination

One of the most developed, institutionalized and widespread PI programmes is the arthritis educator programme in which arthritis patients teach and assess the musculoskeletal examination (total or specific joints). Since the 1980s, it has spread to other schools in the USA, Canada, and Australia, and thence to several other countries, more recently appearing, apparently independently, in Switzerland and the UK. Long-term stable funding has come largely from pharmaceutical companies. The patients (Patient Instructors, Patient Partners, Patient Educators, or Arthritis Educators) receive intense structured and standardized training from physicians within the biomedical model; there is a strong emphasis on anatomy and the reliable assessment of the performance of the joint examination using a standardized checklist (Gruppen et al. 1996). The autonomy of the patient as educator is limited, but in some programmes patients also teach about psychosocial issues and the experience of living with arthritis. Learners are generally preclinical medical students, but some involve clinical level students, postgraduates, and physical therapy students. In general, arthritis educators are used in addition to interactive small group discussion and computer-assisted learning. Because of differences in programme design and evaluation methods, it is difficult to draw strong conclusions about outcomes. Student satisfaction is high although in comparative studies students tend to prefer being taught by specialists. Some programmes employ arthritis educators because of a shortage of specialists. Students taught by patients generally have equivalent examination skills to those taught by specialist physicians (Oswald et al. 2011a) although the teaching style is qualitatively different (Oswald et al. 2011b). Patient satisfaction is high and no adverse effects of being a patient teacher have been noted.

Senior mentor programmes

Senior Mentor Programmes (SMPs) emerged in US medical schools in 2000 to improve attitudes of students towards older people and reduce ageism as part of the evolution of geriatrics curricula in the face of a rapidly aging population. At least 20 programmes have been developed,
all with a primary goal: to provide students an experience with older, well adults. The first wave of programmes that developed between 2000 and 2005 with John A Hartford Foundation and Association of American Medical Colleges support had such promising results that other medical schools subsequently adopted or adapted their own SMP. Detailed descriptions of eight of the original programmes were published in a special issue of *Gerontology and Geriatrics Education* (Stewart and Alford 2006). The SMPs vary greatly in format, including length (from one day to 4 years), whether required or elective, and extent of integration into medical school curricula. Most have a mixture of social activities and formal assignments that students and mentors complete together through interviews or standard assessment instruments (e.g. medication review), but differ in the extent to which the relationship between students and mentors is viewed as a defining aspect of the programme. Students and mentors need to respond to role changes as the relationship and the nature of academic activities evolve. In programmes that last 3 or 4 years, students find it challenging to sustain the relationship and to fulfil SMP obligations during the clinical years.

SMPs use older adults who are basically well and living in the community with no cognitive problems. Most programmes appear to have no difficulty recruiting mentors and some have waiting lists, though all struggle to recruit an ethnically and socioeconomically diverse pool of mentors, an issue raised frequently in descriptions of other patient-as-teacher programmes. Student and mentor acceptance is high, there is a positive effect on student attitudes towards older adults and there is some indication that the experience promotes student empathy and patient-centredness (Eleazer et al. 2009). For example, Breytspraak et al. (2008) found that an intergenerational relationship developed between medical student and senior mentor, characterized by affective reciprocity (empathy, intimacy), instrumental reciprocity (such as advice, role modeling, support), and the discovery of similarities and differences. SMPs appear to be sustained by the medical school because they increase the visibility and acceptance of gerontology, and are economical and easy to operate (Eleazer et al. 2009).

A different model that addressed some of the same concerns about helping physicians to provide better care for the elderly is the ‘Council of Elders’ (Katz et al. 2000) in which community elders were invited to function as ‘Senior Faculty’ to whom medical residents in a geriatrics rotation presented their challenging and heartfelt dilemmas in caring for elderly patients. Particular attention was paid to the preparation felt necessary to build a dialogue relationship between participants from two very different worlds—i.e. different generations and cultures. Unfortunately it is also an example of how patient-as-educator initiatives
are often short-lived—this can be for various reasons: for example the amount of work required may not be sustainable, champions leave, institutional support (including funding) is lacking, or because the initiative was only ever intended as a time-limited research project and not an ongoing programme.

**Mental health**

People with mental health problems are involved in the education of medical students and trainee psychiatrists as well as mental health nurses, clinical psychologists, social workers and interprofessional mental health teams. A general review is provided by Livingston and Cooper (2004) and a detailed practical guide by Tew et al. (2004). Most of the extensive literature relates to involvement in non-physician training, and most comes from the UK. In 2005 the UK Royal College of Psychiatrists made service user and carer involvement an accreditation requirement of postgraduate training programmes in psychiatry through, for example, selection of trainees, planning of training, sharing experiences, interview skills training and giving feedback on performance (Fadden et al. 2005). Patients have identified that they can contextualize the part mental health plays in people’s lives, dispel myths and fantasies; offer positive aspects of mental health to counterbalance negative media portrayals, and illustrate diversity, hope and recovery (Dogra et al. 2008).

Although most psychiatry trainees see benefit to learning about patient perspectives, they have concerns about the representativeness of views expressed and the potential undermining of physician authority; few support patients being assessors because of concerns about objectivity. Indeed, the involvement of people with mental health problems raises some of the thorniest issues in the patient-as-teacher movement. For example, the widespread stereotypes of mental illness, including irrationality and irresponsibility, make the credibility of mental health patients as educators suspect. In the pervasive medical model professionals have the power and legitimized expertise to define the mentally ill as lacking in competence, and contact in a psychiatric hospital setting does not reinforce the view of a patient as an equal partner or member of the community (Scheyett and Kim 2004). On the other hand, patient involvement challenges the traditional role of professionals as experts and requires a new value base with a three-way partnership between professionals, service users and carers where the contribution of each is recognized, valued and respected by the others (Fadden et al. 2005). Academics perceive difficulties in working with mental health service users in the classroom because of assumptions of unpredictability, need for supervision and possible inability to cope with the demands of education (Felton and Stickley 2004). Those who
genuinely attempt to work in collaboration with a patient find they become more aware of their own biases, assumptions and understanding of mental illness (Bennett and Baikie 2003).

Bringing together members of groups with a history of tension to discuss challenging issues and build mutual understanding requires attention to process and the creation of a safe environment for sharing. Techniques such as facilitated dialogue have been used when the aim is to change attitudes (Scheyett and Kim 2004). A number of approaches have been developed to legitimize the involvement of mental health patients through training, co-teaching and accreditation of patient teachers (e.g. consumer tutors) and academic appointments such as ‘Service User Academic’ (Simons et al. 2007). However, this transition from user to academic has led to charges that service users who become part of the educational culture are of limited value as they have become distanced from their experiences and so are not representative of other individuals with mental health problems. In this respect service users are in a no-win situation because as patients they are perceived as incompetent and irrational but neither are they accepted as professionals in the education system (Felton and Stickley 2004).

Parents as teachers

Parents as teacher programmes present learners with a holistic understanding of life with a chronically ill or disabled child—in order to promote family-centred care. They may also aim to prepare professionals for work in an interagency, interprofessional environment in collaboration with families. The most common models are the single home visit to a parent and child with a chronic condition and the family attachment programme in which preclinical students follow a family for a period of time, e.g. through pregnancy. US medical schools provide some of the best developed and long lasting examples in which parents are explicitly recognized as teachers and have been integrated into the curriculum, for example in paediatric residency training (Blasco et al. 1999), paediatric clerkships (Johnson et al. 2006), or throughout the undergraduate curriculum in multiple courses (Hanson and Randall 2007). Each programme involves parents in multiple roles—typically participation in curriculum development, panel discussions, interviews and home visits. A usual feature is involvement of a core group of activated parents, either a pre-existing community advocacy group (such as Parent to Parent Vermont), or a group created especially for purpose. These groups partner with faculty to make decisions about the curriculum, as well as provide a pool of parents for teaching purposes, and are often responsible for recruitment, training and support of new parent teachers. Reports of these programmes emphasize the inclusive developmental process and
describe educational activities but have little information on student perspectives beyond acceptability. Other roles that parents may play include fostering interviewing skills, acting and role playing, sharing experiences of being a patient (e.g. students accompanying parents on a clinic visit), and collaborating in mutually beneficial service-learning activities (e.g. students providing respite care) (Blaylock 2000).

Patient involvement in other health professional programmes

Patient (service user and carer) involvement in the education of health and social care professionals has become expected practice in many countries, especially in the training of mental health professionals, although only in the UK and, to a lesser extent, Australia, has it become mandatory. In the UK involvement of service users or patients is a requirement at preregistration level for nurses, midwives and health visitors, and involvement in social work education was formalized with the introduction of the new social work degree in 2003. The British experience therefore provides the most complete understanding of the obstacles and opportunities that occur with systemic involvement. Although nursing, social work, and mental health workers are the major professions that involve patients in education; an international conference on patient involvement in health professional education in 2005 was also attended by representatives from pharmacy, occupational therapy, physical therapy, chiropractic, and psychology (Farrell et al. 2006). The intent of involvement is to promote the social model that puts service users at the centre of their care. Major goals are to remove attitudinal barriers, challenge stereotypes, tackle social exclusion, and redress historic power imbalances, especially in the case of people who use mental health and social services. In social work education, for example, underpinning values include respect, equality, genuine partnership, social inclusion and empowerment, and involvement is designed to change the power dynamics between clients and social workers (or between students and clients within practice placements) that make it difficult for clients to share experiential knowledge and contribute to the knowledge base of social work (Anghel and Ramon 2009).

Benefits have been shown in a few studies (Barnes et al. 2006) but there is little evidence of sustained impact on student learning. Making patient involvement a mandatory requirement has resulted in tokenistic involvement in many cases with a failure to fundamentally challenge existing power structures in educational relationships (Felton and Stickley 2004). It has also highlighted the barriers that exist in higher education to the development of authentic partnerships: requirements at
the institutional level include strategic leadership and direction, access to local links and networks, and attention to those organizational and cultural issues that require creative solutions and infrastructure to support involvement (Gutteridge and Dobbins 2010). One of the most developed examples of sustained and authentic involvement at an institutional level is Comensus at the University of Central Lancashire, a faculty-wide initiative to involve service users and carers in the education of health and social care professionals across all schools and departments in the Faculty of Health (McKeown et al. 2010).

**Outcomes of patient involvement**

A consistent theme in reviews on patient involvement is lack of clear and measurable educational outcomes. The quality of the literature is generally low, as assessed by accepted criteria for quantitative and qualitative studies (Towle et al. 2010). Most studies are descriptive; some evaluation of short-term outcomes is reported for a subset of initiatives (primarily in the teaching of clinical skills), but few studies have rigorous experimental designs. Interventions are usually described only once, soon after implementation (often of a pilot project) along with preliminary evaluation data, usually student satisfaction and patient views. Reviews by Morgan and Jones (2009) and Jha et al. (2009a) provide summaries of the state of the art and note some evidence of short-term benefits to students and the patient teachers, and lack of evidence of long-term impact on students or the healthcare system. 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. However, some of the recurring themes and more notable studies are identified in the following sections.

**Learners’ perspectives**

Most studies report high learner satisfaction with patient involvement. 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, especially for intimate examinations (Jha et al. 2009a, 2010). Comparisons of student perceptions as reported in pre/post-programme questionnaires indicate that students become more sensitive to the needs of vulnerable populations; and their 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. Students
learn physical examination skills equally well from patient teachers as from physicians (Oswald et al. 2011a).

Although few papers report student learning beyond post-encounter evaluation 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 an individualized approach to the patient (Klein et al. 2000). Studies of effects on subsequent practice are rare. In one follow up study of health professionals in a Masters level Community Mental Health course, all participants described how their practice had developed to enhance user involvement, and a higher proportion of their service users reported good user-centred assessment and care planning compared to a control group (Barnes et al. 2006).

The few negative experiences documented are almost always following sessions with people with mental health problems, and are associated with perceived antagonistic attitudes, unbalanced views, lack of representativeness and mixed views on the usefulness of feedback received (Morgan and Jones 2009). Other studies report that students are sometimes concerned about becoming a burden to patients. Patient attachment and mentorship programmes may provide the first real, long-term exposure that students have to patients and can be emotionally testing, especially if the patient’s health deteriorates. Faculty support for students and having formal closure of the student-patient relationship are helpful (Towle et al. 2010).

**Patients’ perspectives**

Benefits to patients occur because they feel their experiential knowledge of illness and the healthcare system should be included in medical education; they like to give something back to the community and feel their experiences can benefit future health professionals and patients (Stacy and 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.

Problems reported by patients starting their new role include concerns about revisiting negative experiences, about being judged by students and about how truthfully their experiences will be represented when students write up assignments (Towle et al. 2010). Consent and confidentiality are major concerns for patients and carers, but the ethics of patient involvement are not well addressed (Jha et al. 2009a). Concerns
can be 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 that 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 and Spencer 1999) and occasional evidence of negative consequences has been documented, for example in relation to mental health (Livingston and Cooper 2004) and intimate examinations (Jha et al. 2010).

Professionals’ perspectives

Few studies have examined the views of health professionals involved in patient-as-teacher programmes. Most 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 (fig. 27.3). Although they support teaching by patients, time to devote to these programmes is a concern (Towle et al. 2010). There is generally less support for expanding the role of patients to curriculum development or formal assessment of students (Jha et al. 2009b).

Figure 27.3
Patient involvement in action.

No specific negative impact on health professional educators has been documented. Some professionals have negative attitudes about involving patients, most frequently related to patients with mental health problems (Livingston and Cooper 2004). Some express concern about possible deleterious effects on patients such as psychological stress, emotional wellbeing, and physical fatigue but the little research on this is inconclusive (Gecht 2000). Some perceive that patients chosen by their
doctors to be involved 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) or that patients who repeat their stories frequently are in danger of becoming professionalized (Jha et al. 2009b). Research is needed to confirm whether these concerns are justified.

Practical considerations

Good practice guides that provide useful information have been produced in the UK for education in mental healthcare (Tew et al. 2004) and social work (Levin 2004). The INVOLVE guides, designed to promote patient involvement in health research, have information relevant to higher education (http://www.invo.org.uk). No such ‘how to’ resources yet exist for medical education but the British Medical Association (2008) published some useful guidelines, especially on the important topic of ethics, including confidentiality and consent.

Each of these guides organizes the key tasks differently, but all identify a core set of issues as critical. These include: leadership (requires a champion); dedicated funding; recruitment of patients (diversity and representativeness); infrastructure for support, training, and supervision of patients; employment and contracting; payment and expenses; capacity building; and evaluation. They are good resources for those needing advice about initiating and sustaining involvement. However, these activities may be more effectively facilitated by designated support and development workers. A network of development workers has been established in the UK which has published guidelines for higher education institutions (Developers of User and Carers in Education 2009). This liaison role, also referred to as being a culture broker or boundary spanner, is one that many academic institutions have found essential to facilitate partnerships with community-based organizations and overcome the large power imbalance.

A guide produced by the Social Care Institute for Excellence (Levin 2004) articulates key practical considerations in ‘preparing for participation’:

◆ Everyone benefits from working on and agreeing the values and principles of involvement as early as possible in the process of developing partnerships.

◆ A comprehensive strategy for involvement makes it easier to include later new roles where progress may be slower or more complicated.
Patient involvement in medical education

◆ Effective participation requires patients, academic staff, administrators, students, and others working together in new ways—an opportunity for development.
◆ Resources (people, time, money and support) are needed to make it work.
◆ Actively promoting and sustaining participation is a process not a one-off event. It takes time to build respectful and purposeful relationships and to give attention to practicalities.
◆ Enthusiasm and goodwill are required; initially only a small number of participants may be available and willing; widening participation is a key task.

Often the words involvement, collaboration, and partnership are used interchangeably. However, working in true partnership with people from the community brings challenges for academics. There are major institutional barriers to the authentic involvement of community members in higher education, including the hierarchical nature of academia, stigma and discrimination, validation and accreditation processes, academic jargon, definitions of knowledge, and inappropriate payment and support systems (Basset et al. 2006). The university, while paying lip service to community engagement and partnership, still views the benefits to the community to be the consequence of its expertise being given out (Towle and Godolphin 2011a). There is little scholarly debate about the benefits to academia of in-reach from the community, or the changes that may occur to the university as a consequence—that is, ‘the reciprocal sharing of resources between the university and its community, each having different forms of assets and social capital’ (McKeown et al. 2010, p. 52). Recognizing the difficulty of achieving authentic partnerships between academia and the community, the North American organization Community-Campus Partnerships for Health has developed a set of partnership principles that have been recognized and applied internationally (see http://www.ccpph.info).

Based on our experience of developing several patient-as-teacher initiatives, we propose a framework that includes examples of the questions to be considered when planning (see table 27.1).
Table 27.1 Example of a planning framework for a patient as educator programme

<table>
<thead>
<tr>
<th>Issue</th>
<th>Questions to consider</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rationale, theory</td>
<td>What are the reasons for involving patients as educators? Does it fit with institutional philosophy? Has the community expressed an interest need? What are the expected outcomes/benefits?</td>
</tr>
<tr>
<td>Institutional/organizational context</td>
<td>Who are the leaders/champions? Are there existing collaborations with community volunteers/organizations? Where does the programme fit within existing curriculum? Is it a research project or curriculum development initiative?</td>
</tr>
<tr>
<td>Planning</td>
<td>What is the organizational structure for planning (planning committee mandate, leadership, membership of faculty, patients, students, decision making)? What resources are available (for start up, continuation)? Is it a pilot project? Who are the learners and how many? Is it required or voluntary (if voluntary, how are learners selected)?</td>
</tr>
</tbody>
</table>
### Recruitment of patient educators

What are the roles (job description)? How are patients recruited (through community organisations, health professionals, brochures, word of mouth, websites)? How are patients screened and by whom (selection criteria, recruitment process)? How are representativeness and diversity managed?

### Curriculum and assessment

What are the objectives (and who decides)? What are the roles of patients in teaching? Design and number of teaching sessions? Learning activities? How will students be assessed and by whom (role of patient)? Where does learning take place (classroom, clinic, community setting)?

### Preparation and support of patient educators

Orientation (written and verbal information), individual or group? Training (what additional skills do patient educators require, initial and ongoing)? Support (support meetings, contact person for problem solving, updates on programme and student progress)? Recognition (honorary titles, payment, letters, certificates, appreciation events)?

### Operational

Staffing requirements, e.g. coordination, administration (job description, new hire, existing position, secondment), qualifications—professional or administrative?
Programme evaluation and research | Evaluation/ research questions? Methods (surveys, interviews, focus groups, reflective journals)? Ethics, confidentiality and consent for use of data? Knowledge ownership and dissemination?

Sustainability | Moving from project to programme? Embedding in the institution? Institutional support through funding, staffing, space?

Some of the most important practical issues related to involving patients are now discussed in more detail.

**Recruitment**

Patients can be recruited through diverse means such as patient advocacy or support groups, community agencies or newspapers, through family practitioner offices or clinics. In our experience, recruitment works best through organizations such as patient support groups, especially those whose mandate includes educational activities such as peer support, and we recommend that academics take time to develop good working relationships with their local organizations. Most not-for-profit organizations have considerable expertise in the recruitment of volunteers for a variety of roles; we have found them to be of great assistance with recruitment of patient teachers. Two important considerations are diversity and representativeness. Recruitment of culturally or ethnically diverse groups is notoriously problematic. Identified barriers include language, the demographic profile of most patient support groups, the deference to doctors found in some cultures, concerns from families about losing face in the community if illness (especially mental illness) is disclosed, and the major power imbalance between academia and people who are already marginalized in society (Warren and Boxall 2009; Yeung and Ng 2011). Representativeness is a concern given the individual nature of the patient experience and that some patients will have a specific issue or agenda. Although some programmes recruit patients who meet specific criteria, such as good communication skills, in general there has been little substantive discussion in the literature about selection, or application of the ideas found in the work of Williamson (2007) about selection of patient representatives for consultation about healthcare services.
Preparation and training

Preparation of patients for their involvement in education is generally agreed to be important but varies widely in method, duration and intensity. Sometimes patients are given learning objectives to be covered with their student partners and there may be some form of training by the medical faculty. Intensive training is most often associated with teaching physical examination skills. Training appears to reduce patients’ anxiety about their teaching role and makes their involvement seem more official and important. However, little attention has been paid to how training might occur within a partnership model rather than as an activity that is ‘done to’ patients by well-meaning experts. Moss et al. (2009) offer one model in which service users and carers played a leading role in identifying their training needs and developing a course to be taken jointly by service users and academic staff. We have found that by working with patient groups that have a mandate for education we are able to recruit many people who already have skills in facilitation, peer support or making presentations that are directly transferable to their role as teachers of health professionals.

Remuneration and status

Payment models range from nothing, to expenses only, to expenses plus honorarium, to an hourly rate. Some patients do not wish to be paid and feel that the satisfaction of making a contribution to learning is sufficient reward; others feel that this is exploitative. Payment is associated with increased formal recognition and status, and academic leaders must be upfront about policies and practices. Payment for involvement may have repercussions for welfare benefit claims and needs to be negotiated locally and reviewed periodically. Traditional institutional policies and practices may create barriers, for example being slow to reimburse expenses, especially to those who are socially disadvantaged (Gutteridge and Dobbins 2010). Recognition by the institution may be demonstrated in the currency of academia, for example, by funding a formal academic position for a service user, or invitation to coauthor articles (Simons et al. 2007). However, the appropriate recognition of patients who teach contains a fundamental tension; do we provide recognition in a form that the academy values or does this turn people into ‘professors’ making them ‘one of us’ rather than marking and valuing their difference?

Retention and sustainability

Most programs have positive feedback from patients—who want to be repeatedly involved. Retention is best in programmes that involve patients in planning, acknowledge their involvement and regularly update...
them on the programme and student progress. Resources to train patients and maintain their skills, and faculty who are committed to working in partnership are essential for sustainable programmes. In an unpublished study of 59 patient-as-teacher initiatives we found that the most important factors for sustainability were leadership, institutional support, and funding. Descriptions of how initiatives representing a range of patient roles have been sustained over time may be found in the case studies developed by Spencer et al. (2011).

**Future directions**

The ongoing publication of new initiatives in the literature indicates that active patient involvement in medical education is increasing. The experience and expertise that patients have to offer continues to be explored, as do issues of working in authentic partnerships with patients and the community. For example, at the University of British Columbia we have worked with people with mental health problems, aphasia, arthritis, epilepsy, and HIV infection to develop patient-led workshops for interprofessional groups of students in which faculty play a supportive, not directive, role (Towle and Godolphin 2013). The patient educators not only run the workshops but identify the topics that they think are important for them to teach. The result is a wider diversity of topics than is usually taught by patients; topics include living with chronic disease, both day-to-day and the journey over time; the diversity of the illness experience; effects on partners and families; physical examination skills; diagnostic challenges; stigma and stereotyping; peer support; recovery; practical aids to daily living; advice about what health professionals can do; and information about support groups in the community.

However, most initiatives described in the medical education literature are single educational experiences the impact of which is limited. If education is to promote partnerships with patients as the basis for healthcare, then we must move from isolated initiatives to coordinated and sustained programmes: a patient involvement curriculum. This will require academic institutions to move from their ivory towers and engage with community organizations in a non-tokenistic way and to develop authentic partnerships at an institutional level. We recommend that medical educators learn from the experience of other health professions about the opportunities and the challenges of systemic involvement. An important consequence will be the way that the academy recognizes the contribution of people from the community who have a distinctive and unique expertise. Patient involvement will force the university to think and talk differently about intellectual authority, the nature of expertise and the role of the teacher, and will impact the current discourse of
teaching in higher education as a scholarly activity, and teaching as a research-based profession (Towle and Godolphin 2011a).

Through scholarly thought and activity, patient involvement in medical education can not only grow as a movement in its own right but can contribute to other contemporary debates in the field such as professionalism, humanism, narrative competence, relationship-centred care, identity formation, moral development, and reflective capacity.

**Conclusions**

- Active patient involvement in medical education is widespread and increasing.
- Decisions to involve patients have originated from sociocultural changes and associated policy responses.
- Development of applicable learning theory and examination of long-term benefits are needed.
- Involvement of patients as teachers requires attention to practical matters not commonly encountered in medical education.
- Involvement of patients in an authentic and non-tokenistic way has implications for medical educators and academic institutions.
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