# Active patient involvement in the education of health professionals

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**CONTEXT** Patients as educators (teaching intimate physical examination) first appeared in the 1960s. Since then, rationales for the active involvement of patients as educators have been well articulated. There is great potential to promote the learning of patient-centred practice, interprofessional collaboration, community involvement, shared decision making and how to support self-care.

**METHODS** We reviewed and summarised the literature on active patient involvement in health professional education.

**RESULTS** A synthesis of the literature reveals increasing diversity in the ways in which patients are involved in education, but also the movement's weaknesses. Most initiatives are 'one-off' events and are reported as basic descriptions. There is little rigorous research or theory of practice or investigation of behavioural outcomes. The literature is scattered and uses terms (such as 'patient'!) that are contentious and confusing.

**CONCLUSIONS** We propose future directions for research and development, including a taxonomy to facilitate dialogue, an outline of a research strategy and reference to a comprehensive bibliography covering all health and human services.

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## INTRODUCTION

Patients have always been central to medical education, but have usually been used to provide passive illustrations of interesting conditions or as part of students' experiential learning in clinical settings.[1] We use the term 'patient' for the sake of brevity, to include people with health problems (service users, clients, consumers, survivors, etc.), their carers (including parents and families) and healthy people (community members, lay people, well women, etc.). The focus of this paper is their *active* involvement, a term we use to describe the involvement of people who are engaged in teaching, assessment or curriculum development because of their expertise and experiences of health, illness or disability and who are aware that they have designated teaching roles, but *not* to describe the involvement of people who role-play patients to express symptoms or conditions they do not actually have (simulated patients [SPs]). We have assembled a comprehensive bibliography comprising about 270 papers from nine different countries published in English between 1970 and mid-2009 (66% since 2000).[2] The majority of these initiatives come from medicine (64%), nursing (15%) and social work (11%); 9% are multi- or interprofessional. This paper reviews and summarises this literature, identifies limitations, and proposes future directions for research and development. In addition to the medical education literature, we draw on that of other professions to provide a more comprehensive review than has been published to date.

### Terminology and language

The language of patient involvement is confused and emotive. The term 'patient' is controversial, but no single alternative is more acceptable. Whereas 'service user' is the favoured term in the UK, it is not common in North America, where the term 'user' is associated with illicit drug use. Patients disagree about the labels with which they prefer to describe themselves[3,4] and their preferences may change during the trajectory of illness. The terms 'user involvement', 'consumer/lay participation' or 'partnership' and 'patient participation' are used interchangeably.[4] Besides the confusion of terms used to describe the patient as teacher, educator, instructor, mentor or partner, the actual meaning of these terms is inconsistent and sometimes ill defined. Women who teach the pelvic examination may be referred to as standardised patients because they have been trained to teach in a standardised way, but at another institution the same role may be designated a 'teaching associate'. There are no simple solutions to these issues, but better recognition and understanding of such semantic problems and their implications are required.

### Spectrum of involvement

There is a wide range of degree in the extent to which patients are involved in health professional education and many variables in the ways they are involved. The Cambridge framework developed by Spencer *et al.*[5] describes attributes of educational settings that shape the learner–patient encounter, including who (patient culture), how (passive versus active role), what (general versus specific problem) and where (community versus hospital). Tew *et al.*[6] describe a ladder of patient involvement in curricular development and delivery ranging from no involvement to a full partnership in which patients and faculty members work together to make decisions about content and jointly deliver educational sessions. We propose a taxonomy with elements of both these models (Table 1) to characterise the degree of involvement. The adoption of such a classification would help to clarify the patient's role and make it easier to communicate the study of different initiatives.

## METHODS

The papers upon which this review is based were collected by:

1. a survey of participants at an international conference;[7]
2. the identification of papers cited in published reviews;[8–11]
3. a comprehensive search of relevant databases, including PubMed, ERIC, Academic Search Premier, Web of Science, EMBASE, Scopus, CINAHL, PsychINFO and Google Scholar;
4. a hand search of all issues of the major education journals in each of the health professions;
5. the follow-up of references listed in relevant papers;
6. a search of electronic links ('related links') from index papers, and
7. a canvass by e-mail of networks of international contacts for relevant articles.

We used a combination of thesaurus and free text search terms, beginning with those used in published reviews. These included the following terms used

*Table 1 Spectrum of involvement: this taxonomy describes a continuum of patient involvement. In all instances we assume that patients represent their true selves (not a simulation). The taxonomy is grounded in six attributes (A–F) and six levels (1–6)*

| **A** | **B** | **C** | **D** | **E** | **F** |
|---|---|---|---|---|---|
| **Degree to which the 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** |
| 1 *Paper-based or electronic case or scenario* | | | | | |
| Patient is focus of a paper-based, electronic or web-based case or scenario | None | N/A | N/A | None | Low |
| 2 *Standardised or volunteer patient in a clinical setting* | | | | | |
| Patient encounter with student is scripted and serves as an example to illustrate or reinforce learning (e.g. teacher asks patient to provide student with history or student practises a clinical examination) | Encounter-based | None | None | None | Low |
| 3 *Patient shares his or her experience with students within a faculty-directed curriculum* | | | | | |
| Patient is invited to share experience; faculty members plan the encounter but patient determines personal comfort and level of participation | Encounter-based | None–low | Brief, simple | None | Low |
| 4 *Patient-teacher(s) are involved in teaching or evaluating students* | | | | | |
| Patient is given preparation for specific teaching role, may actively question students, may be involved in giving feedback and evaluating students' performance | Variable | Moderate | Structured, extensive | Low–moderate | Low–moderate |
| 5 *Patient-teacher(s) as equal partners in student education, evaluation and curriculum development* | | | | | |
| Patients are involved in many aspects of educational delivery, development and evaluation, beyond specific courses to the curriculum as a whole; this is a true partnership in which patients make meaningful and valued contributions to decision making | Moderate–extensive | High | Extensive | Moderate–extensive | Moderate |
| 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 (5) above but with additional institutional policies that ensure involvement in decision-making bodies within undergraduate, graduate and continuing health professional education | Extensive | High | Extensive | High | High |

N/A = not applicable

alone and in combination: patient/consumer/service user/carer/lay/public; involvement/participation/collaboration/partners*; teach*/educat*/learn*/instruct*, and curriculum/medical education/social work education/nursing education/interprofessional education, etc. Our interest was primarily in the *active* involvement of people who are *not health professionals* as it is reported in peer-reviewed and *scholarly* literature. The following criteria were applied to identify papers in scope.

### Inclusion criteria

- Papers must refer to patients (clients, service users, community members, carers, etc.) engaged in active teaching or in an education development role.
- Patients must be engaged in teaching in their areas of expertise, including their own experiences of life, wellness, illness, disability and the conditions that affect health (e.g. culture, living conditions).
- Papers must refer to people working in the health professions, including medicine, nursing, mental health nursing, midwifery, occupational therapy, physical therapy, pharmacy, dentistry, social work and speech pathology.
- Papers could have any publication date.
- Papers must be published in English.
- Articles must represent descriptions of and research studies into educational programmes or courses, and could include conference papers and letters.
- Articles could include review papers.

### Exclusion criteria

- Articles that represented discussion or opinion papers, unless of significance (e.g. papers that were frequently cited).
- Conference abstracts.
- Papers that described persons taking on the roles of patients or expressing symptoms of conditions they do not actually have (SPs).

Papers were categorised by discipline (nursing, social work, multi- and interprofessional, medicine and other). Because of the large number of publications pertaining to medicine, this category was subdivided into papers relating to clinical skills, musculoskeletal examination, intimate examinations and a 'general' sub-category. We wrote and reviewed research summaries for the resulting papers in order to agree on a higher level summary for each category of the bibliography. We performed a 'quick skim' to identify those papers which provided a clear description of methods, evaluations or innovations. We used the criteria of Côté and Turgeon[12] (for qualitative criteria) or the Best Evidence Medical Education (BEME) checklist[13] (for quantitative criteria) to identify the 'best' quality papers (although few scored very highly) with which to illustrate key points of the literature summaries.

We used the gaps that emerged from the research summaries to develop an extensive list of research questions. These were circulated to about 65 international opinion leaders in health professions education, journal editors, user groups and individual patients, from whom we received 36 responses. We considered their comments and additions in our compilation of directions for future research.

## HISTORICAL DEVELOPMENT OF ACTIVE PATIENT INVOLVEMENT IN MEDICAL EDUCATION

### Patients as teachers of clinical skills

Programmes that feature the patient as an instructor of clinical skills (physical examination and communication skills) were developed in the early 1970s from Barrows and Abrahamson's concept of the 'programmed patient'[14] to address problems doctors encountered in teaching clinical skills. Studies reported in the literature provide evidence of the acceptability, short-term effectiveness and cost-efficiency of the approach. A patient instructor (PI) programme began at the University of Arizona in 1974,[15] when Stillman and colleagues observed that there was little supervised or objective assessment of students' examination techniques. The first PIs were mothers who were 'programmed' to play a role, but a similar programme at Michigan State University allowed mothers to teach from their own experiences.[16] Later, Stillman's group utilised PIs as 'themselves' to teach and evaluate physical examination and communication skills.[17] A 'symptomatic' PI programme, started in 1977, involved out-patients who were taught about their medical conditions, how to examine themselves and how to teach students to detect abnormalities.[18]

When Stillman moved to another school, she 'couldn't find that incredible pool of brilliant patients with chronic stable disease'[15] and turned to SPs instead. By then (the late 1970s), Barrows and colleagues[15] had developed sophisticated simulation techniques, the foundation for the wide and varied use of standardised patients today. Use of the PI concept began to decline apart from the teaching of intimate female and male examinations and musculoskeletal examinations.

Inspired by Barrows' early work, Kretzschmar[19] developed the first gynaecology teaching associate (GTA) programme in the late 1960s. In his programme, the SP evolved to the 'live manikin' (represented by an anonymous draped nurse who gave minimal feedback on how well students imitated instructors' examinations) and subsequently to the 'professional patient GTA', who represented both patient and instructor. By the early 1980s the use of GTAs had become widespread in North American medical schools; male TAs were introduced to teach the genito-rectal examination, but these latter programmes did not become as well established. The Netherlands, Sweden, Belgium, Australia and the UK have adopted GTA programmes more recently. The objectives of GTA programmes may include not only the teaching of technical skills, but also teaching about attitudes towards women and women's health issues, including well women checks and contraception.

The arthritis educator programme, which involves arthritis patients trained to teach and assess the musculoskeletal examination (total or specific joints), also emerged from the SP model at the University of Arizona.[20] This is a long-lasting initiative that has become embedded in many medical schools in the USA, Canada and Australia. Long-term stable funding for the programme has been provided by pharmaceutical companies. Patients are trained through an intense standardised training programme.

**Patients in other teaching and educational roles**

Programmes that involved patients in roles other than as teachers of clinical skills first appeared in the early 1990s as part of a movement for active patient involvement created by the convergence of trends in health care delivery, policy and research that emphasise the active participation of the community and individual patients in many aspects of their care (Table 2). A broadening of the biomedical model of medicine to a biopsychosocial model prompted the recognition that true patient-centred care involves a meeting of experts, comprising health professionals with biomedical expertise and patients who are experts on their own personal and cultural backgrounds and their own stories of illness.[21] As service delivery in westernised countries is now characterised by an ethos of partnership (patient-centred care, shared decision making, the promotion of self-care), which values this expertise of patients, health professional educators and patients increasingly recognise that such partnerships must inform the foundation of health professional education.[1,6]

Examples[2] from the 1990s include schools in the USA that involved children with developmental disabilities and their parents in teaching paediatric residents and medical students. In the UK workshops run by professional adult actors with learning disabilities were designed to promote positive student attitudes towards these conditions. Other patient-teachers were people with AIDS, cancer, mental illness and carers of patients with dementia. The first examples of community-based attachments in which patients were clearly identified as 'partners' in learning were reported.

Two important literature reviews have recognised this increasingly active role for the patient in medical education. In 2000 Spencer *et al.*[5] reviewed the role of the patient in medical student education, noted examples of good practice that promote more active participation and provided a theoretical understanding of how patients could contribute to medical education. In 2002 Wykurz and Kelly[8] noted that a more active teaching role was being undertaken by patients in the USA and the UK and linked this to concepts of the expert patient in managing chronic disease. Their systematic review of 23 articles concluded that when

*Table 2 Drivers of active patient involvement in health professional education*

| |
|---|
| Governments seek to make health services more responsive to the needs of the public and also to contain costs by encouraging self-care, especially among the increasing numbers of patients with chronic conditions ('expert patients') |
| Health care professionals have adopted patient-centred care as the basis of good practice |
| The law and ethical guidelines for consent to medical treatment have increasingly incorporated the notions of shared decision making (between doctor and patient) and informed choice (by the patient) |
| Patients have become more empowered, in part because of dissatisfaction with the quality of care received in the past, but also in response to the growth of a consumerist mentality in society which is fuelled by the Internet |
| Academic institutions, including medical schools, are keen to demonstrate that they are socially responsive and many have developed outreach programmes to engage their local communities |

patients were supported, trained and paid, they could become colleagues in medical training rather than simply representing a teaching resource.

Since these two reviews were published, we have witnessed an increasing diversity of roles and patient expertise, and the extension of such involvement to postgraduate and continuing professional education.[7] The aim of many programmes is to sensitise trainees to the needs of underserved populations, specialties that are in need of more doctors, or complex conditions such as childhood chronic illness, mental illness and care of elderly patients. Senior mentor programmes in the USA that engage students with older adults are designed to address all of these needs[22] and were developed as part of an overall strategy to increase medical school geriatric content.

## PATIENT INVOLVEMENT IN THE EDUCATION OF OTHER HEALTH PROFESSIONALS

In nursing and social work education, patient involvement, usually referred to as service user (and carer) involvement, is recent and exists primarily in the UK, where user involvement in the education of health professionals is mandated by government.[23] Programmes are driven by a philosophy of patient care based on principles of partnership between practitioners, service users and carers.[4] Many involve people with mental health problems. Objectives include the enhancement of partnerships between nurses and patients, being able to identify and work with the limitations of patients and carers, the validation of patient experiences, the design of therapeutic interventions congruent with patient needs, and the teaching of principles of equality, patient empowerment and service user involvement.

Repper and Breeze[9] reviewed the involvement of service users and carers in professional education (mostly nursing) and identified the following approaches: gaining consumers' views through surveys, reference groups, conferences and invitations to join existing groups; involving consumers in the production of learning materials, and involving consumers as teachers and assessors.

There are few published reports of patient involvement in other health professions education (one paper each from physical therapy and pharmacy),[24,25] although government policy appears to have stimulated this work in the UK. The role of the patient-teacher in working with multiple health professional groups and in interprofessional education is also gaining recognition.[26] Many of these initiatives refer to postgraduate or continuing education (in-service training) in, for example, mental health teams.

## LITERATURE SYNTHESIS

The following section is based on information from reviews of patient involvement in medical education,[5,8,10,11] nurse education,[9,11,27] mental health training[9,11,28] and social work,[9,11,29] as well as a synthesis of the references in our bibliography.[2] We will cite a small number of the 'best quality' papers (see Methods) to illustrate certain key points.

### Learners' perspectives

Most studies report high learner satisfaction with patient involvement. Pre- or post-programme questionnaires show that students become more sensitive to the needs of vulnerable populations, and their assumptions and attitudes improve significantly with respect to chronic illness, disabled children, family involvement, mental illness and senior care. Students report increased confidence and reduced anxiety when learning clinical skills from patient-teachers because they receive immediate feedback in a non-threatening environment. Students are able to learn physical examination skills equally well from patient-teachers as from doctors.

Few papers report student learning beyond the post-encounter evaluation,[11] but there is evidence that teaching by patients has lasting impact in the areas of technical skills,[9,30] interpersonal skills, empathic understanding and developing an individualised approach to the patient.[31,32] Studies of effects on subsequent practice are rare.[11,33]

Students are sometimes concerned about becoming a burden to patients. Patient attachment and mentorship programmes often provide the first real, long-term exposure of students to patients. This can be emotionally testing, especially if the patient partner's health deteriorates. Faculty members' support for students and the facilitation of formal closure of the student–patient relationship are helpful. In the clinical years some students find it difficult to free up sufficient time to spend with their patient-mentors.

### Patient perspectives

*Views on involvement*

Patients feel their experiential knowledge of illness and the health care 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. 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.[34] Senior mentors enjoy the companionship of students. Patients generally feel well treated by students.

Anxiety reported by patients, when starting their new roles, 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 processes which include clear explanations of the purpose and importance of patient involvement, the obtaining of informed consent, limiting the medical information provided to students to that necessary to their learning, and the provision of strict guidelines about confidentiality.

*Recruitment and selection*

Patients are recruited through diverse means such as patient advocacy or support groups, community agencies or newspapers, and through family practice offices or clinics. However, the recruitment of culturally or ethnically diverse groups is problematic. Although some programmes find it difficult to recruit enough patients, senior mentor programmes in the USA are well publicised locally and have waiting lists of seniors who are willing to participate. Some programmes recruit selectively to ensure that patients meet specific criteria, such as having good communication skills, but this raises issues of representativeness.

*Preparation and training*

Training for patient-teachers varies widely in method, duration and intensity. Sometimes patients are given learning objectives to be covered with their student partners and receive some form of training by the medical teaching staff. Intensive training is most often associated with teaching physical examination skills. Training appears to reduce patients’ anxiety about their teaching roles and makes their involvement seem more official and important.

*Remuneration and status*

Payment models range from no payment to expenses only, expenses plus an honorarium or an hourly rate. Payment is associated with an increase in the formal recognition and status of the role. 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.[7] Recognition by the institution may be demonstrated, for example, by the application of a formal academic title such as ‘service user academic’ or by an invitation to co-author articles.[35]

*Retention and sustainability*

Most programmes receive positive feedback from patients, who indicate that they want to be repeatedly involved. The best retention rates are achieved by programmes that involve patients in planning, acknowledge their involvement and regularly update them on programme and student progress. Resources to train patients and maintain their skills, and faculty members who are committed to working in partnership, are essential to the sustainability of programmes.

### Professional perspectives

In general, health professionals involved in patient-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 doctors. Faculty members enjoy being involved as facilitators although finding the time they need to devote to these programmes is a concern.

Some doctors have expressed concern about possible deleterious effects on patients in terms of their emotional well-being and physical stamina, but the little research on this topic is equivocal.[36] Some are also concerned that patients who are chosen by their doctors to be involved may either feel obligated to fulfil the commitment or, conversely, may feel the commitment entitles them to preferential treatment, both of which are likely to blur professional boundaries.[34]

Some studies report negative attitudes about involving patients, most frequently in relation to patients with mental health problems.[28] There are times when service users' views differ from those of the professionals who provide their care and there is conflict over whether users' views should be balanced, clarified or corrected. Some faculty members perceive that their own expertise may be devalued.

## LIMITATIONS OF THE LITERATURE ON PATIENT INVOLVEMENT

The literature on patient involvement is hard to find through simple search strategies. Wykurz and Kelly,[8] and Repper and Breeze[9] identified similar numbers of citations (about 2000) of which less than 2% were relevant. The keywords used to index papers lack consistency and a wide variety of descriptive terms are used in abstracts. Searching is made difficult by the lack of agreed titles for the patient-teacher. We found 18 different titles used to describe patient-teachers in 41 studies of patients who teach intimate examinations. Publications are scattered in many different journals and there is little cross-referencing by authors: a recent paper from the UK about the use of patients for teaching intimate examination skills made no reference to the 20+ years of literature about GTAs from the USA. The reviews by Wykurz and Kelly,[8] and Repper and Breeze[9] have only one paper in common.

The lack of standardised terminology to describe patient involvement creates inconsistencies in the scope of review articles. We followed the same inclusion criteria as Wykurz and Kelly[8] ('patients engaged in an active teaching role'), but a recent review by Jha *et al.*[10] emphasised the 'patient' rather than 'active involvement' and excluded the teaching of clinical skills by healthy people, but included patients who did not have defined roles as teachers. Consequently, 11 of the 47 papers reviewed by Jha *et al.*[10] do not meet the inclusion criteria for our bibliography. It is difficult to compare studies without an agreed taxonomy.

Much of the literature is descriptive and few interventions have been rigorously evaluated. Very little is informed by explanatory theory: the papers by Katz *et al.*[33] and Rees *et al.*,[37] which explore the social issues surrounding how students learn 'with' rather than just 'about' patients, are refreshing exceptions. Most descriptions provide insufficient information and few use more developed qualitative research methods. Experimental studies give inadequate information about the interventions and research design and most evaluation is at the level of self-reported perceptions. A recent review of initiatives in the UK by Morgan and Jones[11] identified 41 reports, of which only two attempted to assess a change in the behaviour of the learner or a benefit to the recipient of care (i.e. Kirkpatrick's Levels 3 and 4).[38] Initiatives are usually described only once in the literature, during the early phase of implementation along with preliminary evaluation data. Some evaluation of short-term outcomes for a small subset of initiatives is reported (primarily in the teaching of clinical skills), but few of these studies used rigorous experimental designs. There are no studies of long-term outcomes or sustainability. Many initiatives are ephemeral and the reasons why some become embedded within the institution are unreported.

## FUTURE DIRECTIONS

### Coordinated programmes for patient-centred learning

Academic institutions are encouraged to venture out of their ivory towers and engage with community organisations in a non-tokenistic way. However, most of the initiatives described in the literature are single educational experiences, the impact of which is limited. If education is to promote partnerships with patients as the basis for health care, we must move from isolated initiatives to coordinated and sustained programmes that develop patient involvement curricula and authentic partnerships at an institutional level.[39] Partnership with patients may require a process such as facilitated dialogue in order to overcome stereotyping and attenuate the intrinsic power differential between health professionals and patients, which is accentuated in higher academia.[33,40]

### Research foci

We suggest that it will be helpful to think of the research that is needed using these four categories:

- *antecedent variables*: the drivers of patient involvement; systematic investigation of these will serve as the groundwork for questions related to the structure, process and outcomes of educational initiatives;
- *structures*: these are an especially important influence on learning in health care;

*Table 3 Examples of research areas*

- Antecedent variables
  - What are the drivers of patient involvement in health professional education, including external (socio-economic, political, funding), institutional (university, academic health centre), faculty members and patient factors?
  - How are these factors influenced by different socio-economic, cultural and political environments?
  - What are the similarities and differences among countries, health professions and disciplines with respect to their approaches, their philosophies and the language (terminology, rhetoric) used to describe these? How do these factors affect the experiences of patients and students?
  - How do local and contextual factors influence what is acceptable, feasible and most effective?
- Structural elements
  - What physical locations help patient-educators feel comfortable in a learning environment?
  - What factors need to be considered when students access patient-educators in the community (e.g. safety issues in inner city areas)?
  - What effect does setting (e.g. home, classroom, clinic, community agency) have on learning?
- Processes
  - What preparation, continuing development and evaluation of patient, learner and teaching staff help to build a cadre of experienced and effective patient-educators?
  - How is the patient's role affected by the level and type of patient expertise, content complexity, curriculum design of activity and the timing of exposure?
  - What are the *meanings* that involvement has for patients? How do these change?
  - What are the similarities, differences and tensions between what patients, students and faculty members want to teach and learn from one another? How should we manage conflicts?
  - What are the most effective educational interventions and assessments that lead to defined outcomes?
  - What educational theories underpin the patient-as-educator approach and how can they be applied to enhance learning?
  - What are the ethical and legal implications of patient involvement?
  - What is the intersection between interprofessional education and patient involvement in health professional education and does collaborative learning add value to learning from patients?
- Outcomes
  - What are the short- and long-term effects on health care professionals (knowledge, skills and attitudes) who have been taught by patients? What are the key outcome measures?
  - What is the impact upon practice? What is the long-term change in post-licensure behaviours?
  - What are the outcomes from the perspective of patient-educators? What was their experience? How did it affect their lives?
  - What is the effect of patient involvement on professional socialisation?
  - What is the impact of patient involvement upon organisations and institutions (e.g. their traditions, beliefs, cultures and learning environments)?
  - What factors result in sustainable patient-educator programmes? What are the successful models that can be replicated?

- *processes*: these are many and include the engagement of patients as individuals and groups, the design of curricula based on patient engagement and the actual delivery of the curricula, and
- *outcomes*: these represent the consequences, expected and unexpected, that should be examined.

Examples of the enquiry needed in each category are given in Table 3. The Patients as Educators Research Collaboration has been established to move forward this research agenda.

## CONCLUSIONS

There is a persuasive rationale for the active involvement of patients in health professional education. There is promise and some evidence of benefits to students, patients, teachers and communities. For patients, involvement in the education of those who will care for them is an intrinsically attractive idea. However, we know too little of how to do it and how to optimise its impact, and we have too little systematic development and evaluation. Every health care profession espouses the rubric of patient-centred care, but, in order to move beyond the rhetoric, we believe that the autonomous and authentic patient's voice must be a core part of the training of all health professionals.

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