Patients as teachers: promoting their authentic and autonomous voices

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Editors’ note: The authors of this toolbox article have been involved in this area of health professional education for many years, and are committed advocates of the inclusion of the patient voice across the continuum of learning and training. The ‘patient as teacher’ movement acknowledges the very active role that patients and communities play in education to complement the learning that takes place during health care delivery and clinical rotations. Patients are thus truly experts, and bring different perspectives and stories to the patient–professional partnership. In this article, Towle and Godolphin give practical guidance in relation to terminology, definition of purpose and learning outcomes, recruitment, governance and ethical issues. They highlight the need for careful selection processes and orientation. Students gain most benefit from longitudinal interactions with the same patients to observe, discuss and reflect on how health and illness change over time. Teachers, learners and patients need to be aware of the boundaries of these interactions; patients as educators have different roles from the patients presenting for health care services, with whom the students interact. Patient voices are also important in curriculum development and assessment.

INTRODUCTION

The patient involvement that we refer to occurs when the student learns with, and from, the patient in a setting distinct from that of patient care. The role of the patient is that of educator, an expert by experience; the role of the professional is as collaborator, to enhance the patient’s autonomous and authentic voice. These formal ‘patient as teacher’ initiatives are a subset of student interactions with patients, and complement the clinical interactions in which students learn from patients. This practical guide to the involvement of patients as active teachers is based on our experiences from over 10 years of bringing patient and community voices into the education of health professional students, supplemented with examples from the literature. We also include perspectives provided by our community partners obtained through their participation in planning committees, interviews and as co-presenters at conferences.

The role of the patient is that of educator... the role of the professional is as collaborator
## The Pitfalls of Language

Terminology is a source of controversy and confusion. Words such as patient, client, consumer, service user and survivor often express power relationships and generate strong emotions. In addition, the range of ‘non-professionals’ involved in education includes caregivers (parents or other family members) and people who may be affected by adverse social determinants of health (seniors, members of different ethnic groups or recent immigrants), as well as community-based, not-for-profit organisations that provide support services. For the sake of brevity we use the term ‘patient’ to encompass all of the above, recognising that the term is controversial – as are the alternatives.\(^1\) Words affect communication and collaboration, particular terms trigger strong reactions and other important discussions get sidetracked by heartfelt feelings. We recommend explicit and continuing conversations about difficulties of terminology and what differences you can agree to live with.

### Clarifying Rationale/Purpose

Recent review articles highlight the many ways in which patients have been involved in teaching students, reflecting different rationales for involvement.\(^1\) It is important to clarify the reasons why you want to involve them and your expectations of their level of involvement. These basic decisions will drive others. Various schemes have been proposed to depict levels of patient involvement (from no involvement to partnership). A simple schematic that we have found useful for communicating with both faculty and community members, based on that developed by Towle et al.,\(^1\) is shown in Figure 1. This shows both different kinds of activities and degree of decision-making authority and involvement at an institutional level. It is not a hierarchy, with level 1 being inferior to level 6; different levels serve different purposes.

### Starting a New Educational Initiative Involving Patients

#### Assemble the team: stakeholders and brokers

Although the starting point is usually a champion in the educational institution, it is important to involve patients from the beginning. Students also help to keep everyone’s focus on the purpose, which is education (not, for example, patient empowerment or better health services, although these may be providential side effects). A broker to bridge the different cultures of community and academia is useful. In the UK an increasing number of higher

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### Figure 1. Examples of patient/community roles in health professional education along a spectrum of involvement

<table>
<thead>
<tr>
<th>Level</th>
<th>Description</th>
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<tbody>
<tr>
<td>1. Patients create learning materials</td>
<td>Patients involved in creating learning materials used by faculty members (e.g. paper-based or electronic case or scenario; course materials; videos). Examples: real patient problems as basis for case-based learning; virtual patient cases (may involve video of patient); use of patient narratives.</td>
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<tr>
<td>2. Standardised or volunteer patients</td>
<td>Standardised or volunteer patient in a simulated clinical setting. Examples: standardised patients widely used to teach and assess communication and clinical skills; clinical teachers may encourage volunteer patients to teach and give feedback; students write-up patients’ stories.</td>
</tr>
<tr>
<td>3. Patient shares his or her experience</td>
<td>Patient shares his or her experience with students within a faculty-directed curriculum. Examples: patients invited into the classroom to share experiences of chronic illness, disability etc.; community-based patient/family attachment programmes; senior mentor programmes.</td>
</tr>
<tr>
<td>4. Patients teach &amp; assess students</td>
<td>Patient-teacher(s) are involved in teaching or evaluating students. Examples: teaching associates trained to teach and assess specific clinical skills (e.g. pelvic or breast examination); parents give feedback to students on communication skills.</td>
</tr>
<tr>
<td>5. Patients as equal partners</td>
<td>Patient teacher(s) as equal partners in student education, evaluation and curriculum development. Examples: patient educators involved in multiple programme areas. Patient educators collaborate in educational decision-making (e.g. curriculum objectives or assessment criteria).</td>
</tr>
<tr>
<td>6. Institutional decision making</td>
<td>Patients involved at institutional level in addition to sustained involvement as patient-teacher(s) in education, evaluation and curriculum development. Examples: patients given a formal position in the institution (e.g. Consumer Academic). Patients involved in institutional decision making (e.g. student selection or reviewing funding applications).</td>
</tr>
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</table>
education institutions employ development workers to forge links with the wider community and to recruit, train and support patients (service users and carers) to contribute to professional programmes. A common question is: how do you find the ‘right’ patients or representatives from the community? One approach is a framework based on different levels of knowledge possessed by individual patients, patient groups and patient representatives. Individual patients know and can describe and judge their own experiences of health care. Patient-group members know about the experiences and views of other patients like themselves. Patient representatives or advocates have often developed knowledge and gained experience in several patient groups and in patient–professional committees or working parties, and have a general and abstract knowledge of common interests. It is useful to work with robust community organisations that have stability, capacity, a long-term commitment to education (public or professional) and cachet in the community. Many of these organisations have staff with a mandate for education or advocacy. They may also have outreach coordinators and social researchers in the community who can serve as patient representatives or be able to suggest or recruit individual patients or group members.

**Build relationships: reciprocity**

Mutually beneficial, respectful and long-term relationships are important to community partners. Too often their experience with institutions of higher education is that of academics who like to quickly get the projects done, papers written, and move on to the next. What is needed is an initial investment of time and energy, and a mechanism to maintain relationships through communication, even when the immediate educational needs have been met. The community does not work to the academic calendar. Working together on projects can overcome the fear of the unknown and build trust and understanding. For relationships to flourish the community clearly needs to benefit from their involvement. Look for opportunities for reciprocity, and explore how involvement in educating health professionals helps organisations fulfill their mandate.

**Establish a steering committee**

We recommend that every initiative be guided by a steering committee, comprising key stakeholders (patients, faculty members and students) with real decision-making authority. Sample terms of reference for such a group are given in Table 1. The presence of students reduces the potential for conflict between faculty members and patients; however, students are transitory and busy, so we recommend that each student member has at least one substitute to ensure a critical mass at meetings. An early task of the committee is to discuss the core values underpinning the collaboration, and to determine a set of guiding principles (see sample in Box 1). Guiding principles that underpin peer support are particularly helpful to address the power imbalances that are inevitably present. Guiding principles should be revisited, especially early in the collaboration, as a way of finding common ground and building trust and respect among the stakeholders.

**PLANNING/DEVELOPMENT OF EDUCATION**

**Educational design**

Successful involvement requires well-designed educational experiences, ideally with learning objectives and outcomes that are co-created by faculty members and patients. The focus should be on cooperative and collaborative learning between students and patients to create an authentic patient-centred model of education. Students benefit most from sustained interactions that permit them to discover the person behind the condition and to develop relationships. Panel discussions or workshops put on by groups of patients provide multiple perspectives and more balanced learning. Focusing on a single patient’s experience runs the risk that students then expect that everyone with the condition will be the same. Co-designing education with people from the community provides opportunities for fun and creativity, and for thinking outside traditional academic pedagogy into new experiential learning ideas – participatory techniques that engage the emotions and imagination. For this learning to be transformative, it is important to include a critical reflection component: e.g. learning journals or diaries, concept maps, peer or group discussion, or story writing.

**Recruitment of patient educators**

Recruitment strategies arise directly from the role that patients are to play. A ‘job description’ that clarifies the expectations and the benefits (see Recognition, below) is useful. Thus patients can judge whether this is a worthwhile and realistic commitment for them. Patients may be recruited through diverse means such as advocacy or support groups, community agencies, advertisements in newspapers or clinics, or through health professionals or existing patient educators. A formal selection process may be desirable, depending on the level of responsibility and degree of involvement. This could include: verbal or written information, with details about the purpose, requirements and application or screening process of the programme; an application form; and possibly an interview. Most not-for-profit organisations have expertise in recruiting volunteers.
and their representatives are particularly helpful in designing a recruitment process and conducting interviews. It is important to involve students in the interview process: they are best suited to sense whether someone would be able to relate to students and facilitate their learning.

**Orientation and training**
This may be a new form of learning for patients, students and faculty members, and they probably all need an orientation. Representatives of the stakeholders, e.g. those on the steering committee, should be involved in the design and delivery of an orientation. The training of patients for their educational roles varies widely in method, content, duration and intensity. It appears to reduce patients’ anxiety about teaching, and makes their involvement seem more official and important; however, it may also reduce the authenticity of their voices. The choice ought to depend on the purpose of involvement and role, and should be consistent with the guiding principles and educational design.

**IMPLEMENTATION**

**Timing and location**
When and where learning takes place (university, health care clinic or community setting) sends a strong message about who controls the learning environment. The location should be accessible (e.g. by wheelchairs and by public transport), and one where patients (especially those from more marginalised communities) feel comfortable.

**Recognition and remuneration**
Payment models range from no payment, expenses only, expenses plus honorarium to an hourly rate. There are many arguments for and against payment: some patients value volunteerism, but others feel that this is exploitative; some institutions cannot provide payment, whereas others require it. Policies should be developed by the steering committee or at least with input.

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**Table 1. Template for terms of reference for a steering committee**

<table>
<thead>
<tr>
<th>Terms of reference sections</th>
<th>Content</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1. Programme or project description</strong></td>
<td>Description of goals and objectives, methods or educational design, target audience, outcomes, timeline (e.g. phases of a pilot project), coordination/leadership and funding</td>
</tr>
<tr>
<td><strong>2. Mandate of the steering committee</strong></td>
<td>Brief statement about overall responsibility of the steering committee</td>
</tr>
</tbody>
</table>
| **3. Tasks of the steering committee** | Specific tasks may include:  
  - Development of guiding principles  
  - Development of specific objectives  
  - Project or programme planning  
  - Assistance with recruitment (of patient educators, students and faculty members)  
  - Development of an evaluation framework  
  - Review of evaluation data and identification of recommendations for future changes  
  - Dissemination of information, including conference presentations or publications  
  - Problem solving and trouble shooting  
  - Securing funding |
| **4. Meetings** | Number of meetings per year; timing, length and usual location of meetings  
  - Payment of expenses (e.g. parking) or honoraria |
| **5. Membership** | Composition (e.g. numbers of faculty members, students and patients/representatives of organisations) and method of selection  
  - Members of committee secretariat (standing members)  
  - Chair or co-chairs, and how they have been appointed  
  - Term for members (e.g. 2 years, renewable) |
| **6. List of Members** | Organised by category (e.g. students or faculty members), with name and dates of appointment |
| **7. Decision making** | Specify decision-making process, e.g. ‘Decisions will normally be made by consensus. If a formal vote is required or the committee is unable to reach consensus, each member will have a vote and a simple majority is required for a motion to be passed’ |
Policies should be transparent, communicated at recruitment and consistent. Forms of recognition as well as, or instead of, payment are important. These include: certificates; personal mementos, such as letters, thank-you cards and photographs (of them with their students); recognition events (receptions) with university leaders; awards; university library privileges; and honorary appointments.

Support for patient educators
Whether support is individual or in a group, face to face or through social media, personal relationships with patient educators are important. Support group meetings provide opportunities for patients to share experiences, ask questions, get feedback, and can serve as a recognition event. Online discussion boards or Facebook groups may work for some. A programme associate, possibly someone in a broker role, may be the first point of contact by e-mail or telephone for answering immediate questions or concerns from students or patients.

Ethical issues
Ethical considerations of involving patients as educators, especially regarding consent and confidentiality, must be thought through. For extended involvement between patients and a group of students it is important to have an agreement or contract that is read, discussed and signed by all parties about what is confidential and what is not, and about care in using social media (an example is available online as supporting information). In a society with much public sharing of personal information, it is a good opportunity for thoughtful explicit discussion about the sharing of health and other personal information. Consent for photography for personal, publicity or academic use is another area for discussion, agreement and written documentation; some patients may not wish to be identified.

Evaluation
Benefits to both students and patients have been documented (Box 2); however, most evaluation of patients as teachers has been of short-term outcomes through questionnaires or small-scale surveys, and few have assessed a change in behaviour in practice or benefit to the recipients of their care. There are rich opportunities for research into the outcomes of patient involvement and the educational process by which students learn from patients.

Box 1. Sample guiding principles
The programme will:
1. Be developed as a collaborative initiative between students, faculty members and community representatives, including patients.
2. Maximise the learning that takes place between students and patients. The role of faculty members is to facilitate, not direct, the learning.
3. Support patients in their role by providing clear expectations about roles and responsibilities, an orientation to the programme, an identified contact person, regular check-points to find out how things are going and a debriefing session at the end.
4. Support students in their learning by providing clear expectations about roles, responsibilities and programme requirements, an identified contact person, an orientation to the programme, regular check-points to find out how things are going and a debriefing session at the end.
5. Include the perspectives of the family, significant others or carers, and informal supports, as well as the patient.
6. Be designed, implemented and evaluated in a rigorous manner, and by scholarly standards.
7. Develop guidelines and rules for governance, student supervision and conflict management.
8. Follow existing university and programme policies relating to academic conduct, professional behaviour and ethics. A specific code of conduct based on these policies and procedures will be developed so that problems are addressed in a timely, fair and consistent manner.
9. Not permit students to participate in patient care or service delivery.

Box 2. Examples of benefits to students and patients

Examples of student learning outcomes
• Enhanced understanding of patient perspectives and increased empathy
• Enhanced confidence in communication and clinical skills
• More positive attitudes towards marginalised or underserved populations (e.g. elderly or disabled patients)
• Heightened interest, motivation and desire to effect change in the health care system

Examples of benefits to patient educators
• Giving back to health service and community; influencing future health care providers
• Therapeutic effects: increased self-esteem, empowerment, new knowledge and insights
• New relationships: companionship, belonging, reduced social isolation

There are rich opportunities for research into the outcomes of patient involvement.

Evidence suggests that educational innovation is more likely to be sustained if it is integrated into the curriculum.

SUSTAINABILITY/ INSTITUTIONALISATION

Champions are important at the start, but unless attention is paid to sustainability, patient involvement initiatives often die when the champion moves on. Although start-up funding may come from a grant or one-off allocation, evidence suggests that educational innovation is more likely to be sustained if it is integrated into the curriculum with institutional support and core funding. Pilot projects demonstrate to budget holders the value of the investment, and hence the initial evaluation should focus on effectiveness and efficiency. Sustainability also requires stable long-term community–academic partnerships, or building and maintaining a cadre of patient educators. Some patients may not be able or willing to continue because of personal or health issues, but a stable pool of educators reduces recruitment and orientation efforts. Experienced patient educators can support new recruits, and are a valuable resource for other projects and programmes: for example, acting as representatives on advisory groups or providing assistance with a new curriculum initiative.

CONCLUSION

Successful patient involvement in health professional education is enhanced by: paying attention to the creation and maintenance of mutually beneficial, respectful, long-term relationships; a coherent connection between rationale, guiding principles and educational outcomes; and the active participation of representatives of community organisations and students in educational design and recruitment of patient educators.

REFERENCES


SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at http://onlinelibrary.wiley.com/doi/10.1111/tct.12400/suppinfo

Data S1. Sample Confidentiality Agreement

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