


WHEN I SAY**When I say ... the patient voice**Jill E. Thistlethwaite¹  | Angela Towle² | Carolyn Canfield² | Darren Lauscher³¹University of Technology Sydney, Sydney, New South Wales, Australia²Faculty of Medicine, University of British Columbia, Vancouver, Canada³University of British Columbia, Vancouver, Canada**Correspondence**

Jill E. Thistlethwaite, University of Technology Sydney, Sydney, NSW, Australia.

Email: jill.thistlethwaite@uts.edu.au

Clinical material in sufficient quantity and variety is readily available in large towns. (p. 232)¹

Abraham Flexner wrote the above words nearly one century ago. A former school teacher, Flexner had an enormous influence on the introduction of the biomedical model of medical education in the United States that subsequently spread globally. His reference to patients as *clinical material* may seem outdated, but similar language still permeates doctors' discourses. We hear health professional students talking about 'practising on patients' and referring to them as 'poor historians'. The patient as a passive recipient of care has even been satirically referenced in popular Western culture. An episode from the Monty Python Flying Circus film, *The Meaning of Life*, features a pregnant woman in labour being wheeled into an operating theatre. She asks one of the doctors what she should do. John Cleese, in character, answers: 'nothing dear, you're not qualified'.² While this sketch dates back 50 years, babies are still typically referred to as being delivered rather than the mother giving birth.

'No decision about me, without me' is a call to give patients a voice and a share in decision making.³ Reworded as 'nothing about me, without me', the phrase represents a cultural shift in which patients have agency in relation not only to their healthcare but also to their participation in clinical research. And, we can add to this, a more active role in health professional education.

Engaging the patient voice recognises that patients are experts. *Meetings between Experts*, published in 1985,⁴ defines patients as experts about their illnesses, living with the condition and learning to understand and manage it. They engage with the professional expertise of the doctor to manage care in partnership. Expert patients have become indispensable at many universities, helping students to gain perspectives not only on the biomedical aspects of ill-health but also

the psychosocial and lived experience. *Patients with lived experience* (PWLA) is a term that derives from phenomenological research methodology and refers to individuals with a first-hand experience of a health issue. These experiences are diverse, and, of course, there are multiple patient voices. In this article, we employ voice as an inclusive and collective noun similar to its use within the research field.⁵

The patient voice should pervade the whole curriculum. We advocate for patients to be involved in all areas of education including curriculum development, learning activities, assessment and evaluation. Health professional schools and higher degree committees should have a membership including educators, practising health professionals, learners and patients. Some faculty may argue that 'we are all patients', which raises the question of how 'patient' is defined. In English, the word patient derives from the Latin 'patior', meaning to suffer or to bear. Most dictionary definitions imply that patients are (passive) recipients of medical treatment or are under healthcare. Although this meaning may be objectionable in some ways,⁶ it does emphasise that we are not all patients all the time. There are numerous accounts by doctors who have experienced accessing healthcare at first hand who then become aware of what it feels like to be a patient, even after decades of being a clinician.

All too often those patients who are involved in education come from a limited demographic—usually those who have the time, means and confidence to volunteer to share their experiences in an academic setting that should be culturally safe. It is important to ensure that patients do not experience any adverse effects from their contributions and that those who share their stories and lived experience are supported during and after what has been called emotional labour.⁷ We need a diversity of voices in the classroom, around the decision-making table, so that we educate future health professionals to meet the healthcare needs of our increasingly diverse populations.

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So far, we have argued for the importance of the patient voice from the perspective of the medical educator. What do patients say in response? Authors Carolyn Canfield and Darren Lauscher have been involved in medical and interprofessional education for many years, in many roles, from direct teaching of students to membership of decision-making committees, for example, curriculum reform, course design and selection policies. These are some of the questions and perspectives that they think health professional educators need to hear and answer.

1. The onus is on the professionals to ask: Why would someone get involved? What are the barriers? What supports are needed? What assumptions do I have? Will they trust me when I invite them or suggest supports? As an Indigenous elder says, it takes 'ten cups of tea' to meet and establish the depth of understanding sufficient to collaborate. Aligning expectations prevents misunderstanding and potential harm. That alignment needs to follow through each stage of developing trust.
2. How do you build sufficient trust to give patients the confidence to tell the truth, to take risks? How do you foster agency in an environment that is rife with status and hierarchy? Trust is necessary to promote agency so that patients have a sense of the legitimacy of their own voice. Authentic experiences are valuable for student learning but make patients vulnerable and can put them at risk. How will you support patients in advance, in the moment and afterwards to avoid harm and improve the educational experience for patient and learner? How do you compensate people for visiting their distinctive experiences—acknowledging the risk? What assurances could be given from the organisation, including successful experience in handling difficult learner/patient situations?
3. Is the patient on the team recognised and given credit for their participation? So often patients do not get feedback or recognition for the quality of their contributions, until they are asked back. Feedback from the academic organiser heightens the relationship. Patients want to learn from their experience how to improve their contribution to health professional education.
4. We want many voices, many views. What groups already offer a safe space as the basis of a partnership? Rather than assigning the job of spokesperson to an individual, can you engage a community with a range of authentic voices? Giving professional educator duties to a patient is an unfair burden. Teaching technology may not be our strength, whereas the power of our voices may be. The idea of the 'expert' patient is problematic for many patient educators who may feel, 'I have expertise, but I am not an expert', recognising the diversity of human responses and circumstances. Patients want their knowledge to be seen as complementary, not competitive, with clinical expertise. The interest in diversity expects that there are individuals out there with a wealth of confidence and experience. We must find them. But if you want people from oppressed, hard-to-reach populations, maybe you need a different methodology for engagement that builds on collective support, for example, by compiling stories as told through theatre.
5. Look outside your own profession's education. What is happening elsewhere in your organisation, community and region? There is a

groundswell of patient and community partnership around the world across healthcare domains of improvement, research and beyond. Lots of strategies for participation are well developed, but not widely known in health professional education. What other disciplines (e.g. community-based research) already maintain relationships with the community? There is a wealth of learning about building trust that is relevant to health professional education.⁸

The four of us have different perspectives but that is the power of diverse voices collaborating: listening to and learning with each other. In so doing, we find greater meaning and enjoyment in our shared quest towards better healthcare for everyone.

AUTHOR CONTRIBUTIONS

Jill E. Thistlethwaite: Conceptualization; writing—original draft; writing—review and editing. **Angela Towle:** Conceptualization; writing—original draft; writing—review and editing. **Carolyn Canfield:** Conceptualization; writing—original draft; writing—review and editing. **Darren Lauscher:** Conceptualization; writing—original draft; writing—review and editing.

DATA AVAILABILITY STATEMENT

Data sharing not applicable to this article as no datasets were generated or analysed during the current study.

ORCID

Jill E. Thistlethwaite  <https://orcid.org/0000-0001-8122-4679>

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