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# LETTERS TO THE EDITOR

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## Can a health professional represent patient views?

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At a recent international conference session about how to involve patients and elicit patient views for consideration during decision making around the provision of health services, a representative of a patient group made a statement that initially angered me, then left me upset and emotional. The statement was that patients who are health professionals were not able to be considered as representatives for that patient group in decision-making fora.

As a health professional who has a chronic health condition that I am still struggling to come to terms with, I came out of the conference session feeling that the very groups that purport to support patients had just negated me, my experiences, and my concerns. I had been thinking of contacting and perhaps joining a local patient support group, but now I am concerned about how common this opinion is. Will I be welcomed by my local group? Will I be listened to as a person or dismissed as someone whose opinions or experiences are less valid than others?

It has taken me a long time to find the courage to approach the local patient group, because my past experience of being a health professional with health problems has not been an altogether positive one. Staff either hurry past me, or assume that I know everything already and don't need the basic information that other patients receive. In situations where I am vulnerable, as you can be as a patient, I am reluctant to ask all the questions I have in case I am seen as a demanding patient or as taking time away from more deserving patients.

Almost everyone will become a patient at some point in their lives and some, like me, will live with a chronic condition for years. Each patient brings to every new situation their prior experiences, knowledge, skills, moral framework, and social systems. I believe that the job that someone has or

the role they play in their family or society should be just one more experience to add, not the sole arbiter of how a person experiences or perceives or adapts to a problem or situation.

I assume the situation must be similar for other professionals when their personal and professional lives cross. I imagine that being a parent who is also a school teacher can lead to similar wariness on both sides, when talking to your child's teacher about their progress at school. But does this mean that a parent who is a teacher cannot be a board member of the parent-teacher association?

I can see that my skills in health technology assessment and my background as a doctor in general practice and later public health would put me in a privileged position as a patient group representative in the decision-making arena. I can see that it would be possible to exploit this - if I were that sort of person - when talking to other patients or lay committee members without this background, but that presupposes the motivation and low professional values.

Do patient groups or their individual members feel threatened by "health professional" patients? Do they think that "ordinary" patient's opinions will be overwhelmed if "we" are allowed in? Do they believe that health professionals cannot represent other people's opinions and experiences? If that is so, how can anyone represent anyone else's opinions or experiences other than their own? Is this opinion widespread or confined to some patient groups only?

If this were an opinion developed after a bad experience with an overbearing health professional patient, then I can understand their reluctance, but that experience should not be used against all such patients. We should work toward a meaningful dialogue between those with experiences and healthcare decision makers. A more inclusive approach may support a more meaningful communication.

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## **Can a health professional represent patient views: HTA response**

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To the Editor:

As a health technology assessment body committed to active patient and public involvement, we at the Scottish Medicines Consortium (SMC) have considered the question above and the views expressed by Dr. Claire Packer and conclude that the answer is “Yes.” As Dr. Packer notes, no patient representative can ever be purely a patient with a specific condition as everyone brings other life experiences, including but not limited to their employment, to their understanding, and perception of their condition. A background in health care will provide different experiences from other backgrounds, but these experiences bring added breadth to the patient perception and, thus, enhance any health technology assessment or other decision making in the health arena.

Clearly a patient with a background in finance, education, or manufacturing industry would bring different experiences, but these are no more (or less) valid or valuable than the experiences of a healthcare professional. Importantly, patient representatives in healthcare decision making have a role to represent as wide a range of patients as possible and not simply themselves. This is a difficult challenge and one which no organization has fully resolved, but there is no reason to expect that a patient with a healthcare background would be any less able to fulfill this role than any other patient. Involvement of several patients from different backgrounds is ideal, and where established Patient Interest Groups already exist, their involvement (subject to appropriate declarations of interest) can be very helpful and avoid over-reliance on individual patients. No individual sub-group of patients should be systematically excluded from the process.

As Dr. Packer notes, healthcare professionals experience the same range of emotional and psychological responses to the development of both acute and chronic illness as other patients, and may struggle to find the support and help that they need. To suggest that their experiences have no relevance or value in healthcare decision making is entirely inappropriate.

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## **Can a health professional represent patient view: Patient organization response**

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To the Editor:

A healthcare professional expressed anger and dismay in response to a comment reportedly made by a patient group representative that “health professionals (even those who are also patients) were not considered as representatives for patient groups in decision-making fora.” I have heard this sentiment before and always believed it begs the question, “What qualifies one to be a patient representative, and are there any disqualifiers?”

Obviously, not just anyone who has a health condition could appropriately represent the “patient perspective” in a decision-making context. He/she would need to know the views of the patients affected by the decision and also be able to represent these views in a multi-stakeholder forum. He/she potentially could be a board member or staff of a patient organization.

Presumably, in a multi-stakeholder forum, the patient representative would advocate for the best interests of the “recipients” of healthcare in the same way as others advocate for the interests of the “regulator,” “public payer,” the “healthcare institution,” and the “healthcare provider.” Could the reviewer, the bureaucrat, the administrator, or the health professional also be a patient? Based on the statistics, at least half of them are. However, they participate in their professional roles, not their personal roles.

The representative for the patient presumably also has other roles in life, but he/she will be speaking in the role of patient. He/she could be a teacher, a chef, a housekeeper, bank executive, lawyer, politician, and, yes, even a dentist, pharmacist, nurse, or doctor.

There are obviously many advantages to having patient representatives at the decision table who can easily understand the perspectives of the other stakeholders and who are respected by the others. There are, however, two key challenges for the patient representative who also has (or had) one of the other stakeholder roles. Can he/she manage the potential conflicts of interest and strongly advocate as a patient? More importantly, can he/she maintain the trust of the patients represented? In reality, these are personal qualifications for any patient advocate, and not all patients have them. The health professional chosen to represent patients just has to work a little bit harder to demonstrate them.

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