

Finally, being a doctor, working in an academic setting, having experience in HTA, and being a patient puts me in a good position to bridge the gaps over prejudice and misunderstanding. Basically, I know how the stakeholders think and feel because I could easily walk in everybody's shoes. Look at your shoes and you can see my feet.

Albert J. Jovell, MD, DPH, PhD
 Email: albert.jovell@uab.es
 CEO, Josep Laporte Library Foundation
 University Autònoma of Barcelona
 Antoni Maria Claret 171, 3rd Floor
 08041 Barcelona, Spain

Who can and who should represent the patient?

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To the Editor:

Why can it be difficult for healthcare professionals to be patient group representatives? First, we will try to clarify what is meant by *representing* a patient group and what is meant by being a *patient*.

Representing a patient group can mean to present a particular expertise, that is, to explain how it is to be a patient with a particular condition or disease. However, it can also mean to speak up for, argue for, or demand (in power-like relationships) on behalf of a certain interest group. Moreover, it can mean to enter into dialogue and negotiations on basis of one's unique experience and perspective.

Correspondingly, what does it mean to *be a patient*, and does an additional role as a healthcare professional alter the patient role? In other words, are healthcare professionals who have a disease patients who happen to be health professionals, are they "sick professionals," or something else?

A patient is normally defined as "the one who suffers" and who needs help and assistance from healthcare professionals. Accordingly, the patient has experience of illness and can guide decision makers toward using relevant endpoints and outcomes. However, a patient can also be seen as a person with a particular experience of the treatment system, social expectations, and power relationships (according to his or her *sick role*). In this latter *patient role*, a patient representative may aim at empowerment, autonomy, and improvement of treatment systems. A third conception of the patient may be as a client or consumer. In this perspective, a patient representative may be one who demands more and better services for his or her group.

In the first two conceptions of *patient*, it may be difficult for a healthcare professional to be a representative. As Dr. Packer herself points out, her experiences as a patient differ from those of other patients. Healthcare professionals behave differently toward her, and she is expected to know more

about the disease and the healthcare system than ordinary patients. Hence, the healthcare professional may have different experiences of being a patient and of the healthcare system than the patients he or she is supposed to represent. But then, if patients are conceived of as consumers, a healthcare professional may be a brilliant representative, as she or he will have more knowledge about the disease, the healthcare system, and about potential diagnostic and therapeutic options.

Another reason why health professionals can find it difficult to be patient group representatives is that patient groups are stakeholders who to some extent define themselves in contrast to other stakeholders, such as health professionals and decision makers. There is a power relationship between patients and health professionals. In such cases, patients may wonder whether a professional really promotes the perspective and interests of the patient group, or whether she or he is influenced by her or his role as a professional. Hence, challenges with trust and conflict of interest may hinder some professionals from being elected as representatives. Professionals as representatives could also inadvertently alienate other patients by moving perspectives and terminology away from the experiential sphere of "lay patients." On the other hand, professionals who "switch perspective" may be brilliant representatives but may get problems with their professional community and identities.

Hence, there are some good reasons why health professionals may well be patient group representatives on decision-making fora. For several equally good reasons, it can be difficult for healthcare professionals to represent patients well. Our conclusion is that healthcare professionals *can be*, but not that they *should be*, patient group representatives. The decision should be up to the lay patients.

Bjørn Hofmann, MSc, PhD
 Email: b.m.hofmann@medisin.uio.no
 Professor
 University of Oslo
 Center for Medical Ethics
 P.O. Box 1130 Blindern
 N-0318 Oslo, Norway
 Adjunct Professor
 University College of Gjøvik
 Department of Health, Technology, and Social Science
 P.O. Box 1
 N-2802 Gjøvik, Norway

Samuli I. Saarni, MD, MSocSC, PhD
 Email: samuli.saarni@helsinki.fi
 Adjunct Professor
 National Institute for Health and Welfare
 University of Helsinki and Helsinki University Central Hospital
 Department of Psychiatry
 P.O. Box 30
 00271 Helsinki, Finland