

# From the Editor

## Working with and for patients

Doctors learn from their patients. They have always done so, especially those treating patients with chronic diseases whose needs they come to know and understand sometimes over many years. These lessons have always been learnt in the clinics and at the bedside without any formal structure. That structure is now to be put in place, so that we shall in future listen to patients, their carers and the public in general, sitting round the committee table.

The need to explore new approaches to clinical practice arises as the major focus of care shifts from the acutely ill to the growing number of patients with chronic diseases. Such patients are now thought to occupy around 60% of our time in western medicine. However, in developing countries, the concept of chronic diseases is often poorly understood by patients and doctors alike, and furthermore, medical training through much of the twentieth century referred chiefly to acute illnesses. The needs of chronic patients are different from those of the acutely ill: few people suffering from left ventricular failure or acute peritonitis would ask for choices. So it is above all in the care of those with chronic diseases that the collaboration with the patient needs to be better understood.

Patients are already involved in many, probably most, organisations concerned with healthcare. The NHS has appointed Mr Harry Cayton as director of patient experience – ‘the patients’ tsar’; patients have long and increasingly contributed to the deliberations of the General Medical Council; the National Institute for Clinical Excellence (NICE) has devised a Citizens’ Council; the *British Medical Journal* has appointed a patient editor;<sup>1</sup> and this College has broadened the functions of its patients’ representatives and will ensure that there is patient involvement at every level.

Two key principles, defined by the Commission for Health Improvement, underpin patient participation,

namely working *with* patients and working *for* patients. Working *with* patients requires that those using services have a say in their care as well as in health planning and rationing. Working *for* patients is necessary in order to ensure that they get the best quality care and treatment. The latter approach requires professional and technical expert advice in order to promote the highest standards ultimately for the benefit of patients. This is the approach adopted by College which will shortly appoint a College Officer to coordinate the patients and carers liaison work.

We can now begin to unravel the criteria for selecting patients to carry out these tasks, addressed by Dr Chris Clough in this issue.<sup>2</sup> The role and expertise of these patients needs to be defined and the questions to be answered also need careful consideration, as NICE have already discovered with their Citizens’ Council.<sup>3</sup> Precise job descriptions need to be constructed. Obviously, those working *for* patients require particular skills. But how should we select patient users of services? After all, most of us fall at some stage into that category. Should we appoint ‘good’ patients, or do ‘difficult’ patients or ‘disadvantaged’ patients give better value?<sup>2</sup> Should we appoint privileged patients from specialist groups while understanding that they often have a particular agenda? And then there is the ‘expert’ patient, so far undefined and often untrained.<sup>4,5</sup> What qualities and what training might be required?

The need to consult the general public and our patients is not in question, but there are limitations. The public perception of medical issues is often distorted by the frequent bias of media reporting.<sup>6</sup> Professionals’ understanding of health risks and their ability to communicate these to patients can be inadequate, and the resulting uncertainties, already difficult for doctors, are at times impossible for patients.<sup>7</sup> Furthermore, patients are not always convinced by evidence-based practice, giving rise to tensions between professionals and patients, for

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example in the recommendations regarding the management of chronic fatigue syndrome/myalgic encephalitis patients.<sup>8,9</sup> Such complex issues will require much consideration in the professional relationship with patients and public. It is therefore important that this College is so active in promoting<sup>10,11</sup> and assessing<sup>12,13</sup> professional values and behaviour, and in its support for the benefits of the medical humanities.<sup>14</sup>

So the lay public in general and patients in particular will rightly have a structure in which they will have a definitive role in promoting the standards of care they expect to receive from the profession. Yet the real listening to patients will always remain in the context of the medical consultation: but from now on, the listening must be translated into action, principally by practising clinicians working with their patients.

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