Editorial

New millennium, new values: citizen participation as the democratic ideal in health care

It seems important and, indeed, privileged to make symbolic statements at a time like this, when we can reflect on the past year, decade, century and possibly 1000 years and attempt to use our insights to make wise prognostications about what will or should happen in the next equivalent period. Of course such anniversaries are defined culturally and are of direct relevance only to some. However, I am sure that few will be able to avoid the hype that will accompany this millennium and it does provide us with an excuse for creative musings about the paths we may tread over the coming years. I intend to use this privileged space to do just that, hoping to provoke a serious debate about values and power in the context of modern health care.

We have witnessed many changes in the provision of health care during this century, reflecting changing socio-economic fortunes and political ideologies. Primarily the system on offer has been increasingly moulded by a nation state intent on providing the means for a dignified life for its citizens, which hitherto had been subject to the vagaries of social class, wealth and luck. In the United Kingdom this culminated in the establishment of a National Health Service in 1948, which was the product of the peculiarities of nationalized wartime provision during 1939–1945, weak and disorganized insurance companies during the 1930s, ideological opposition to the market in health care by the post-war Government, and concessions to the medical profession to allow the continuation of private practice. For many this represented, and still represents, the jewel in the crown of the welfare state. Significantly it gave a foundation to the third dimension of citizenship, social rights, to add to previously won civil and political rights, thus giving all citizens the potential for access to effective involvement in social and community life [1].

Since that time, in Britain and elsewhere, although debate has raged as to the financial viability of public health care, whether it be funded through taxation or insurance, successive governments have continued their commitment to a public service. Until the 1980s that is, when fundamental cracks in the economic orthodoxy, that started to appear after the oil shocks of 1973, gadged wide. This period ushered in a new orthodoxy wedded to a belief in the invisible hand of the market and utility maximizing individuals who would make better choices than that offered as staple fare by centralized administrative systems. Neo-classical economics replaced the Keynesian model and brought with it a world of deregulation, decentralization, privatization, competition, internal markets, contracts and new means to control the professions. It has led to the establishment of purchaser–provider splits in organizations and various degrees of managed care. All of this would appear to be occurring at a rapid rate in response to an increasingly pervasive economic globalization and information technology.

Like many policy changes, this dramatic shift in health care provision has occurred as a direct result of perceived failures in previous systems or economic conditions, which provide an opportunity for other ideologies to take root. Needless to say, perhaps, most of these changes have not been subject to prior testing, which makes evidence-based policy something of an oxymoron. Fundamental assumptions about individual behaviour and functioning of markets have been found wanting in many regards, not least being the supposed efficiency that would be brought through increased competition, even if it was accepted that this was the primary goal.

While the USA is pursuing competition apace [2], deep concerns about the negative effects on equity and management costs have persuaded the British Government to redirect its strategy, even if it is not a wholesale rejection of the previous model. For example, the language is now one of ‘primary care co-operatives’ (in Scotland) or ‘primary care groups’ (in England and Wales), which are to replace the previous dual system of primary care, based on whether general practitioners had direct control over where contracts were placed. Collaboration and partnerships are the new buzz words of health care, with competition besmirched by its palpable failure to ensure equity or meet the efficiency goal, as well as a ‘proliferation of low-trust relationships’ [3]. The new direction, however, is based on centrally set and monitored standards, a system which itself was replaced by the previous Government due to its apparent failure to improve quality of care. As Maynard [4] argues ‘... governments swing from one unevaluated structure to another, ever reluctant to evaluate, learn and improve, ...’

There has been an interesting discussion recently in the
that has revisited an old debate about whether ‘patient’ is the appropriate word to use to describe an active participant in health care. The contributions have ranged from the view that it is anachronistic, in that a patient implies ‘quiet suffering’ and ‘passivity’, making an active patient ‘a contradiction in terms’ [6], to the other end of the spectrum where remote etymology is seen to be of little value in understanding new meanings of words and where the alternatives, such as health seeker, client, customer, consumer or user, are deemed worse [7]. Stacey [8], writing from a sociological perspective, recognized the inappropriateness of the term ‘consumer’ to describe the relationship of patients to the health care system, as they present themselves as ‘work-objects’ to have things done to, rather than for them. Rarely passive, patients themselves and professionals both work on patients who are ill or injured. The notion of the patient as a passive and objectified body emerged in parallel with the development of surgery in the late eighteenth century [9], to which the physical environmental context was added in the mid-nineteenth century [10], and the subjective personality by the mid-twentieth century [11].

Language is a key semiotic representation of our society, communicating what is deemed to exist and, at the same time, being used to try and persuade us of what should exist. It functions to represent our social, political and economic worlds and it is no surprise, therefore, to find it changing over time and, furthermore, being highly contested. In the same way quality is equally contestable, being defined by different stakeholder groups to determine their own agendas for action and what is to count as worthy of meaning or measurement [12]. In the case of recent ideology, it has been clear to many commentators that the political objective has been to recast social relations in health care as one mirroring an enterprise culture [13]. In these circumstances health service goods and services have to be bought and sold as in any other sector. In other words, in moving from something with use-value health care becomes just another commodity to be traded on the basis of its exchange-value. Neo-classical economic representation of supply and demand thus translates doctors, nurses and other professionals into producers and patients into consumers.

Of course, as the debate in the British Medical Journal exemplifies, such atomistic representations do not accord with everyone’s view of the health care process. Health to a large extent is the product of social, cultural and economic contexts and to a limited degree by individual life style, in which health services play an important but probably minor role. Patients clearly ‘suffer’ illnesses and we are all patients at one time or another in our lives. Use of this terminology for those who benefit from health services when they are not ill, such as those seeking health promotion or pregnant women, clearly suggests an etymological problem. Nonetheless, to deem them simply as consumers would certainly deprive them of their crucial role in the production of health and health care alongside health care professionals and others.

What it does point to, perhaps, is that, although current mores reject the traditional paternalistic modes of health care delivery, there is still the perception that members of the public have no more than an end-state relationship to the system, as customers rather than co-producers of the design, delivery and evaluation of health care.

Boundaries serve to organize our professional lives, to provide spaces within which we manage our resources and take responsibility for what happens. Unfortunately, as Beacock [14] and Dickinson and Deighan, in a recent Journal editorial [15], argue, they also serve to foster fragmentation and place barriers in the way of quality improvement. Patients are increasingly recognized to have the competence and, for many, the desire to be treated as people who know how to make diagnoses, treat themselves and monitor their progress. As a minimum most health systems today recognize the need to hear their patients’ opinions about the quality of health care, through the use of satisfaction questionnaires and measures of expectations. However, although this is more participative than simple patient consent, this is still at a fairly minimal level of consultation.

If we take the ‘customer as king’ view of quality then we can think of the public having the power to make all decisions, calling on professionals when it was felt appropriate to gain expert knowledge and information, selecting those aspects that were felt to be useful. In such a role professionals would become subservient while patients would have to accept full responsibility for their decisions, which is unlikely to be a very comfortable position for either party. The alternative position would be somewhere in between the dominance and consultation positions, labelled the shared decision-making model, where information, decisions and implementation are shared, as is the responsibility for them [16]. The quality agenda under this framework would be based on a set of values that would lead to a more participatory and democratic system of health care.

Last year at the European Forum on Quality Improvement in Health Care in Vienna, I conducted an exploratory, role-playing exercise on the topic of shared decision making, by asking the 50 or so participants to act out doctor or patient roles according to the three models: paternalistic, shared, and customer-as-king decision making. The ‘patients’ were asked to play their role on a consistent basis at three successive ‘health centres’, in each of which they met with a particular type of general practitioner. In other words, there was one centre where the doctors were always paternalistic, in another they always wanted to share decisions, and in the third they would assume that patients were the sole decision-makers. Patients would act as submissive, expect to share decisions, or demand the right to decide everything. The resulting matrix of possibilities is shown in Figure 1, where examples of the potential outcomes have been inserted from the participants. It is interesting to note some of the tentative conclusions that could be derived from this kind of scenario, albeit needing to be tested in more realistic conditions. Firstly, few ‘patients’ and no ‘doctors’ were happy with the ‘customer-as-king’ position. Secondly, although most people thought that the shared decision-making model was the ideal, it proved to be very demanding of time. Thirdly, the paternalistic model offered the greatest opportunities for efficiency, although it angered many of the ‘patients’.
due weight to participation in decision making and a genuine shift in power from professionals and managers, while at the same time not abandoning patients to having to take on the full burden of responsibility for difficult decisions with uncertain and ambiguous outcomes. There is a long gestation period ahead for the development of shared decision making, but the methodology of deliberative group techniques, such as focus groups, citizen panels and citizen juries, is growing fast and being used to inform policy making at all levels of governance. As Berwick [14] admonishes: 'It is the burden of good leadership to make the currently unthinkable thinkable, to question the obvious, to make the present systems unavailable as options for the future.'

Let us debate the values that will lead us into the next phase of health care, recognizing the growing clamour for a part of the action from those who need health care now and in the future. If it is not to be a more democratic way of operating, then I suggest we put that to the vote.

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References


