LIFE AND DEATH **Iona Heath**

The emperor's new constitution

A proposed constitution for the NHS is superficial and hypocritical

A draft constitution for the NHS in England was published on 30 June 2008 and is open for public consultation until 17 October (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085814). A constitution establishes the fundamental principles according to which an organisation is to be governed and is usually composed and published at its inception. The NHS has celebrated its 60th birthday this year, and you have to wonder why a constitution is needed now.

The current draft is seven parts platitude, two parts mendacity, and one part hypocrisy. The worst excess of platitude comes in the statement of six values listed at the end of the constitution. The fourth of these concerns compassion: "We find the time to listen and talk when it is needed, make the effort to understand, and get on and do the small things that mean so much—not because we are asked to but because we care." I find this particularly sickening precisely because it describes what I and so many others working in the NHS try to do every day—but our aspiration is cheapened by this kind of trite and superficial writing. I almost feel insulted.

Yet of course it is never possible to do all the extra small things for everyone all of the time. On wards and in general practice waiting rooms and emergency departments up and down the country, staff members avoid making eye contact with patients, not because they lack compassion, not because they don't care, but because there are not enough staff, because there are not enough hours in the working day, and because need has to be identified and prioritised. Pretending that the world of the NHS is not like this further betrays an already demoralised staff.

Mendacity appears most obviously in the sixth of the seven "principles that guide the NHS": "Public funds will be devoted solely to the benefit of the people that the NHS serves." This is clearly untrue when public funds are diverted into private profit through the private finance initiative and the ever increasing use of private, for-profit provider organisations—unless, of course, the people that the NHS serves are intended to include the shareholders of these for-profit companies.

The most striking example of hypocrisy comes in the preamble setting out requirements for renewal of the constitution, which are to be legally binding. These "will guarantee that the principles and values which underpin the NHS are subject to regular review and recommitment; and that any government which seeks to alter the principles or values of the NHS . . . will have to engage in full and transparent debate with the public, patients and staff." This is written just after the current government, with its programme of systematic privatisation and commercialisation of health care, has instituted what is arguably the biggest shift in the principles and values of the NHS since its foundation, with no sign of full and transparent public debate.

Patients and members of the public in my part of London have now spent several months trying to understand why and how local practices have been taken over by United Health Group, a huge multinational company. The decision making is meant to be transparent, but it seems anything but; and, in reality, ordinary people have no power to influence decisions, because there is no democratic accountability in the running of the health service other than nationally through the general election process.

The draft constitution conveys no awareness of the ever recurring conflict between one person's preference and another's need, and it seems to have no recognition that funding depends on politically acceptable levels of taxation. There is a lot about the responsibility of individuals and families to contribute to their own good health but absolutely nothing about the socioeconomic determinants of health or about how the organisation of society systematically undermines the health of its poorest and most vulnerable members. J K Galbraith wrote about "the inescapable fact that the modern market economy accords wealth and distributes income in a highly unequal, socially adverse and also functionally damaging fashion." Governments have a key responsibility to protect the poor from the excesses of the market. The draft NHS constitution has nothing about this. There is also nothing about the teaching of the next generation of healthcare professionals in the NHS and almost nothing about the central importance of research. No mention is made of the systematic reclassification of much of the ill health associated with old age as requiring social care, which individuals must pay for, rather than health care, which is provided free, and none made of the continuing neglect of the health needs of people with dementia.

"Our aspiration is cheapened by this kind of trite and superficial writing. I almost feel insulted"

Back in 1991 Margaret Thatcher's government published the *Patient's Charter for England*, which was greeted with a distinct lack of enthusiasm by most healthcare professionals. Rereading it now, alongside the new draft constitution, I am struck by how much better that charter was—how much less condescending and how much more practical and concrete.

Instead, we now have platitudes of the current draft constitution. These cover areas that are crucially important to patients and staff—areas such as dignity, respect, privacy, confidentiality, fairness, and justice. Yet all these are in fact undermined to a greater or lesser extent by the way the NHS is organised and governed. The constitution is yet another top-down rhetorical exercise that will not make the world a better place.

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MEDICINE AND THE MEDIA

Why is the press so nasty to NICE?

The British press has declared open season on NICE, reports **Nigel Hawkes**

Embattled and almost friendless, the government body charged with assessing the cost effectiveness of drugs is enduring a torrid spell. The National Institute for Health and Clinical Excellence (NICE) has always been controversial, but the torrents of abuse thrown at it in the past two months have set new standards, in volume and in vitriol.

Andrew Dillon, NICE's chief executive, has been called "Dr Death" and the organisation he runs described as "a bunch of fat cat executives who sit in their plush office playing God." Callous, nasty, terrible, barbaric, and with "a long and devastating history of denying care to those who need it most," NICE has run the gamut of *Roget's Thesaurus* as its critics compete for the most damning adjectives the English language can provide. The British national press has run more than 200 stories about NICE since the beginning of August, all but a handful of them critical, some stretching the boundaries of reasonable comment to breaking point.

Is this a conspiracy hatched by the drug industry, stung by the often disobliging judgments of its products made by NICE? Is it a media feeding frenzy, fuelled by ministerial timidity and NICE's own inability to rebut the criticism effectively? Or has the press actually got it right, despite its shrill and bloodthirsty tone?

Journalists like having fun, and it is fun to join a baying mob running towards the sound of breaking glass

NICE's response has been to argue that rationing is inevitable in any cash limited system—which nobody denies—and that its model for picking winners and losers is the most rational yet designed. But the more that NICE's bosses appeal to logic, the easier the press finds it to portray them as pointy headed intellectuals who are indifferent to the fate of those their decisions affect.

The row started in August when NICE concluded that four treatments for kidney cancer (sunitinib (Sutent), bevacizumab (Avastin), sorafenib (Nexavar), and temsirolimus (Torisel)) were not cost effective for patients with advanced or metastatic cancer. None are cures, but they can extend life. NICE was also in hot water for refusing to allow patients with rheumatoid arthritis to switch from one anti-tumour necrosis factor drug to another and for taking more than two years to approve ranibizumab (Lucentis) for treating wet macular degeneration—a period, critics asserted, during which 5000 people lost sight that might otherwise have been saved.

The kidney cancer guidance triggered an onslaught. The *Daily Mail*, whose finger is never far from the trigger when NICE is within range, ran a series of long stories and features, all critical. The *Times* published a hot headed opinion piece by Jonathan Waxman, professor of oncology at Imperial College, reprised several days later in the *Daily Mail*. The *Sunday Times* was the delighted recipient of a letter from 26 oncologists saying: "It just can't be that everybody else in the world is wrong about access to innovative cancer care and the NHS is right." NICE's judgments, they said, were "poor" and "unsuitable."


A DEATH SENTENCE

Fury at kidney cancer drug veto

GRAN'S £10k LIFELINE

By now the red tops were weighing in. It was Carole Malone, in the *News of the World*, who called Andrew Dillon "Dr Death." This man, she said, was neither a doctor nor a scientist but a bean counter in a posh suit with the power to tell people to "eff off and die." Perhaps the lowest blow of all was landed by the Conservative party, which alleged that NICE spent more on spin than on assessing drugs, a claim that the *Mail* gleefully put on its front page and that the *Daily Express* and *Daily Telegraph* also published. This claim was based on a wilful misreading of NICE's accounts—in fact it spends less that 1% of its budget on its press office—but, by then, who cared? It was the glorious 12th, and NICE was a lovely fat grouse rising in front of the eager guns.

Should NICE care? The British press in full cry may not be a pretty sight, but neither can it be dismissed as irrelevant. People read newspapers, and among those people are ministers, who often take them more seriously than do those who write for them. Journalists like having fun, and it is fun to join a baying mob running towards the sound of breaking glass. Few resisted the temptation except the *Guardian* and the *Independent*, which offered a cautious defence of NICE all but drowned out by the rest.

Claims that the press chorus was being orchestrated by the drug companies can be dismissed. Of course, the industry dislikes NICE and helps provide arguments to undermine it, either directly or through patients' groups it helps fund. But in this instance it was a far more dangerous foe, the aforementioned doctors, who gave licence to the papers to pursue their quarry.

Mr Dillon often claims that NICE's panels are stuffed with clinicians, although it is unknown for any of them to come forward to defend their decisions. But by deliberately excluding from its panels those with a direct experience of the drug at issue, NICE almost guarantees that any negative decision will be opposed. A politically astute system would seek to incorporate these experts—to make use of their judgment (which is no small thing) and to implicate them with the decisions reached, however unpalatable. A technocratic system, such as that used by NICE, seeks to exclude them on grounds of suspected bias. To make an enemy of the very people who know most about a disease and its treatment is politically naive.

NICE's claims of scientific objectivity are also undermined by its refusal to come clean about the full details of its economic models. Science should be an open process, transparent to all. NICE's methods are not, therefore, really scientific but authoritarian. Their authority derives from an economic model that is effectively a "black box" churning out results that nobody else can verify.

Finally, NICE's apparent threshold for approving drugs is, by its own admission, arbitrary. The figure of £30 000 (€38 000; $54 000) per quality adjusted life year has no evidential base and has not been changed since NICE was launched nine years ago. If it was right then, it is hopelessly adrift now; if it is right now, it was wrong then. An organisation claiming expertise in economics cannot choose to disregard inflation.

So with a few changes NICE could strengthen its hand. It could also try a bit harder, as it did in its early days, to engage journalists rather than merely responding to them. But the unpalatable fact is that the United Kingdom now spends three times as much (in cash terms) on the NHS as it did in 1997, and yet patients still cannot get the drugs that other systems provide.

Taxpayers find this puzzling. Patients who are dying find it intolerable. NICE pays the price in angry headlines, while ministers sit on their hands.

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