

# Patient power needs to be built on strong intellectual foundations

The balance of power in health systems needs to be shifted so that people are enabled to live the life that they want rather than having to fit in with professional and commercial views, says **Nigel Crisp**



## NIGEL CRISP BIOGRAPHY

Nigel Crisp was chief executive of the NHS and permanent secretary at the Department of Health from 2000 to 2006. Before that he held various senior managerial posts in the NHS, including that of chief executive of Oxford Radcliffe Hospitals NHS Trust, South Thames regional director of the NHS, and London regional director. Since 2006 he has been involved in international development work, and writes and speaks widely on global health.

**T**here are many parallels between the current reforms in the English NHS and those under way elsewhere in the world. Almost all these programmes focus on market solutions and on changing the relationship between the public and private sectors. Most also emphasise prevention and the need to combat the epidemic of non-communicable diseases.

These similarities are particularly striking because different countries have such different economic prospects. China, India, and other fast growing economies are investing heavily in healthcare, and many plan to introduce universal health coverage. Many European states, in stark contrast, are looking at ways of cutting costs and restricting coverage.<sup>1</sup> Meanwhile the poorest nations remain dependent on foreign aid and have the worst health and the worst access to healthcare.

It is also striking that no country has yet been successful in giving its citizens a truly central role in improving health and healthcare, preferring instead to rely almost exclusively on economic and professional levers.

People are defined in terms of economic and professional frameworks and are reduced to being mere consumers in need of satisfying or passive patients in need of treatment or education. They are not seen as active participants in their own right.

The dominant mindset sees the world in economic and professional terms. We need to offset this by developing an equally powerful intellectual framework and language based on the roles and rights of each of us as individuals and citizens. To do so we need to ask the seemingly simple question: what do we want from our health service?

### Economic and professional dominance

Economic thinking is now as dominant in health and public services as in other areas of life. This can be helpful. Specifying services, measuring inputs and outputs, offering incentives for following evidence based guidelines, and promoting some competition between providers can all help to make improvements. However, this approach also creates problems. It can take years before health providers are given financial incentives to adopt new types

of service that patients value such as email or telephone services or providing treatment in the community rather than in hospital

The increasing complexity of payment systems and over-reliance on competition and on paying separately for different elements of care can lead to poor coordination and restrict collaboration.<sup>2</sup> Additionally, as many people who have had to deal with private health insurance know, a purely contract based system can lead to costly disputes about whether particular conditions or treatments are covered.<sup>3</sup>

Moreover, patients as consumers are no match for educated and high status clinicians offering them services. This can be particularly problematic when the professionals are backed by good marketing. I was reminded of this by a wealthy man who told me that he could get a whole body scan at a very good price. He and his brothers saw it as too good an opportunity to miss and signed up for scans. Sure enough his scan revealed an anomaly, but thankfully, he told me, the company had been able to do more tests to confirm that there was nothing wrong. The brothers now plan to have scans annually. It reminded me of the US advert:

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"Show your man you care, buy him a CT scan for Christmas." There are many ways to create anxiety and turn it into an income stream.

Health professionals, however, can even-up this relationship by guiding people through their decisions and choices and helping them navigate the system. This is at the heart of NHS policies designed to give general practitioners budgets and decide which services best suit their patients' needs. However, there are also risks with an over-reliance on the views of professionals.

The most obvious is that the clinician is not the patient. These perspectives are necessarily different, as Professor Hilary Thomas so movingly described in her transition from eminent cancer expert to vulnerable patient.<sup>4</sup> We each make our own trade-offs as we balance the "burden of treatment"—the discomfort, indignities, inconvenience, and other costs—against the potential and sometimes uncertain benefits of the treatment.<sup>5</sup> The doctor doesn't always know best.

There is also the risk of conflicts of interest. It is remarkable that we expect our NHS clinicians to ignore their own interests when they treat us, and wonderful that our trust is so often justified. The NHS structure and the UK professional education system go a long way to support this by largely aligning patient and doctor interests within a framework of shared values and expectations. A British doctor of Indian origin recently reminded me that doctors aren't always trusted in the same way. In India, she told me, it is generally assumed that doctors have a personal interest in the treatment they prescribe. Patients are much more vulnerable in countries without an NHS-type framework of shared values and practices. Even in England, however, the risks of conflicts of interest and reduced trust are increasing as doctors take on new financial roles.

Over-reliance on a professional perspective can also lead to turning every possible issue—from physical disability to childbirth or social problems—into a medical problem that requires a professional (and often a commercial) solution. This trend is illustrated by the new edition of the *Diagnostic and Statistical Manual of Mental Disorders*, which lists 120 new disorders, a 50% increase since 1980. Its previous editor described the increase as a "wholesale imperial medicalisation of normality" and a "bonanza for the pharmaceutical industry."<sup>6</sup>

Similarly, my experience as a policy maker taught me that over-reliance on an economic perspective can be counterproductive: economic incentives can change behaviour but by themselves rarely motivate professionals, who are mostly driven by a much wider group of concerns.<sup>7</sup>

### Empowered citizens

One common approach to these problems is to create structures, safeguards, and audits to reduce the risks. However, these are burdensome and energy sapping. An alternative is to build up the power of patients and citizens as a counterbalance to the dominance of economic and professional frameworks.

Most NHS clinicians in my experience work hard to make decisions with their patients, although, sadly, many patients still feel excluded.<sup>8</sup> Innovative practitioners have developed new ways of managing and thinking about the patient-professional relationship. These may involve putting their knowledge at the disposal of patients by "conferring agency" on them<sup>9</sup>; helping "flat pack patients" assemble the pieces provided by professionals to fit their personal needs<sup>10</sup>; or otherwise empowering them as partners in everything from drug discovery to service design.

One example of this is the transfusion unit in Jonköping, Sweden, set up at the instigation of a patient, where all patients now manage their dialysis at times to suit them.<sup>11</sup> It epitomises the concept of "health citizens" who are "motivated and competent to take control of their own health and well being and to participate in personal and community choices that promote well being."<sup>12</sup>

Many disabled people and their organisations have led the way here, refusing to be medicalised—and infantilised—and demanding to be treated as active citizens and live a normal life. One leading figure, Baroness Jane Campbell, has gone further and called for all patients to be treated in the same way.

It is interesting that many traditional communities—such as the Inuit and First Nations in North America—exemplify this approach by blending the expertise of Western professionals with their traditional wisdom to provide

services that fit in with their culture and practices and are therefore more likely to be used effectively.<sup>13</sup> It is the community that sets the terms of the relationship with the professions and not the other way round. This example not only draws out the importance of cultural aspects in healthcare but illustrates the point I have argued elsewhere that richer countries have much to learn from others.<sup>13</sup>

The NHS has supported many patient centred initiatives. For a decade "expert patients" with long term conditions such as chronic obstructive pulmonary disease have offered advice and support to fellow patients and helped redesign services. Direct payments are being extended so that more people with disabilities and long term conditions receive their own budget and can, if they wish, employ their own carers. New health apps are beginning to enable patients to look after their own health and use health services more effectively. Patient perceptions are being factored into assessments of health outcomes through patient reported outcome measures

(PROMs) and other routes. Moreover, as recent articles in the *BMJ* have described, patients are finally to be provided with access to their records in the government's latest information technology strategy.<sup>14</sup>

These initiatives are linked to a burgeoning academic and practitioner debate around patient satisfaction, engagement, and empow-

erment. Sadly, current examples of failure to listen to patients' concerns in Mid Staffordshire and elsewhere add weight to the need for much greater attention to this area.<sup>15</sup>

### What we want from the NHS

These developments raise the question: why aren't patients and citizens truly at the heart of health reform? Most of these ideas aren't new, and many are in government policy; why don't they have the weight and influence to determine what happens in reality?

This is partly about power. British citizens, unlike the Inuit, don't set the terms of their relationship with the professionals and economic interests. The whole system is geared towards citizens and patients fitting in with these interests. I believe this reflects the fact that there is as yet no satisfactory and coherent

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intellectual underpinning for an alternative approach based on the counterbalancing power of patients and citizens. Excellent research and analysis on engaging patients provides some of what is needed.<sup>16</sup> However, even such useful concepts as patient empowerment, engagement, satisfaction, and choice rely on consumerist and professional concepts and work broadly within the assumptions of the system.

We can break out of these constraints by asking what we really want from the NHS and health professionals. In doing so, we can begin to create the necessary intellectual underpinning. I suggest this might rest on three pillars: our desire for autonomy and independence; the reality of our interdependence; and the framework of rights and responsibilities that balances the two.

My starting point is that what we want is, of course, to be treated, cured, nursed back to health, and helped to stay healthy. All of these, I would argue, however, relate to a deeper desire to be able to live our lives as we want to. Our language reveals this: we want “to get our lives back” when we are ill and to be able to “live independently” as we get older or to “choose” to put ourselves into the care of others. Although our lives may become constrained by illness, age, or disability, we still value our ability to act and to make decisions. All too often, healthcare takes this autonomy away from us. I have told elsewhere the story of a friend, who when she was in intensive care overheard doctors saying that she should not be resuscitated because her quality of life was so poor. She, however, was determined to judge for herself whether her life was worth living.<sup>13</sup>

There is a substantial literature about the purpose of healthcare being to restore function and to enable people to enjoy their health and wellbeing. I want to go further, however, and add that each of us individually is the judge of our own quality of life. Functionality alone is not enough. My simple formulation is therefore that healthcare should help us to live as autonomously and independently as possible and to “live a life we have reason to value.”<sup>17</sup>

We are also as individuals interdependent with others in our society in terms of our health as with anything else. The social environment, our relationships and social structures, affect

our health as profoundly as the physical environment. Poverty, isolation, and pollution damage health while social engagement and affluence can improve it.<sup>18</sup> We are more likely to be healthy individuals in a healthy society—just as, thanks to globalisation, the health of individual nations is linked to the health of the whole world.

The global declarations of the rights to health and to healthcare provide a balance between the needs and demands of individuals and those of their neighbours and of society as a whole. More locally, the NHS with its framework of values and practices—some now contained in the NHS

constitution—embraces a range of explicit and implicit rights and responsibilities. It is a social contract between citizens and nation. The NHS is not a mere health insurance system—as a consumer perspective would suggest—where patients only have

consumer rights. We each have rights as citizens to expect that our doctors, nurses, and others will do their best for us just as we expect other public servants in education or the police or armed forces to do the same.

I believe these three concepts—interdependence, interdependence, and rights—can together provide the foundation for a different way of looking at healthcare.

### Practical implications

These ideas have very practical application. The aim of any system determines what gets measured and what gets done. If the NHS and social services explicitly shared the aims of promoting autonomy, independence, and interdependence—and if they were measured and assessed on it—it would lead to new priorities and different expenditure patterns. The problems of current boundaries are well understood, with elderly patients, for example, trapped in hospital and losing functionality every day because the NHS has treated the acute phase and handed over responsibility to others. Genuinely shared responsibility would accelerate current NHS policies for integrated services and go further—requiring sharing of everything from practices and structures to information systems and, most profoundly, professional education and training. It would start to shift power and change the mindset.

This shift could be reinforced by policies across all areas of government and beyond that explicitly support people’s autonomy and independence—not simply as consumers but as active citizens responsible for their own health. These would align well with many current social trends. Our interdependence could be encapsulated in NHS governance and brought to life in redefining the relationships between citizens, clinicians, government, and public and private organisations. Similarly, our rights and responsibilities to health as citizens could be rewritten in a new social contract between citizens and country. Taken together, these actions could start to build up the necessary intellectual weight and social power to challenge the current economic and professional dominance and shape a different sort of health system for the future.

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